DOCUMENT RESUME

ED 455 032 PS 029 686

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TITLE Are We Responding to Their Needs? States' Early Experiences Serving Children with Special Health Care Needs under SCHIP. Occasional Paper Number 48. Assessing the New Federalism: An Urban Institute Program To Assess Changing Social Policies.
INSTITUTION Urban Inst., Washington, DC.
SPONS AGENCY Mott (C.S.) Foundation, Flint, MI.; Annie E. Casey Foundation, Baltimore, MD.; Kellogg Foundation, Battle Creek, MI.; Henry J. Kaiser Family Foundation, Menlo Park, CA.; Ford Foundation, New York, NY.; Robert Wood Johnson Foundation, New Brunswick, NJ.; David and Lucile Packard Foundation, Los Altos, CA.; John D. and Catherine T. MacArthur Foundation, Chicago, IL.; McKnight Foundation, Minneapolis, MN.; Commonwealth Fund, New York, NY.; Weingart Foundation, Los Angeles, CA.; Fund for New Jersey, East Orange.; Lynde and Harry Bradley Foundation, Milwaukee, WI.; Joyce Foundation, Chicago, IL.; Rockefeller Foundation, New York, NY.
PUB DATE 2001-05-00
NOTE 48p.; Additional funding provided by the Stuart Foundation.
AVAILABLE FROM Urban Institute, 2100 M Street, N.W., Washington, DC 20037. Tel: 202-833-7200; Fax: 202-429-0687; e-mail: paffairs@ui.urban.org; Web site: http://www.urban.org.
PUB TYPE Reports - Evaluative (142)
EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Children; Chronic Illness; Delivery Systems; Disabilities; Enrollment Influences; *Federal Programs; *Health Insurance; *Health Needs; Identification; Outreach Programs; *Special Health Problems
IDENTIFIERS *Childrens Health Insurance Program; Special Needs Children

ABSTRACT

Noting that children with special health care needs (CSHCN) make up one of every six children eligible for the State Children's Health Insurance Program (SCHIP), this study examined how SCHIP responded to the needs of children with chronic illnesses and disabilities. This qualitative study was based on the implementation experiences in 18 states. Key findings were organized into six areas. Findings indicated that none of the study states made overt efforts to target CSHCN for enrollment. Benefit packages under separate programs were more limited than those covered by Medicaid. In almost every state, SCHIP programs relied on managed care, with CSHCN being served through the same care systems serving all children. Three states reported policies that exempted CSHCN from cost sharing or somehow protected them from undue expense. Waiting periods disproportionately affected families of CSHCN. States reported difficulty in identifying and enrolling large numbers of CSHCN into SCHIP programs. Based on findings, two changes to current policy are recommended: (1) permit SCHIP coverage to "wrap around" existing private health insurance for selected priority populations; and (2) encourage or require states to broaden their waiting period exceptions policies to allow CSHCN to drop private coverage if that coverage is significantly limited or expensive. (An appendix lists the key SCHIP and Medicaid contacts in the study states. Contains 30 references.) (KB)

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Occasional Paper Number 48

SCHIP
State Children's Health Insurance Program Evaluation

Assessing the New Federalism
An Urban Institute Program to Assess Changing Social Policies

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This report is part of the Urban Institute's *Assessing the New Federalism* project, a multiyear effort to monitor and assess the devolution of social programs from the federal to the state and local levels. Alan Weil is the project director. The project analyzes changes in income support, social services, and health programs. In collaboration with Child Trends, the project studies child and family well-being.

This occasional paper is part of a comprehensive evaluation of the State Children's Health Insurance Program, primarily funded by the Robert Wood Johnson Foundation and the David and Lucile Packard Foundation as part of the Urban Institute's *Assessing the New Federalism* project. Additional financial support came from The Annie E. Casey Foundation, the W.K. Kellogg Foundation, The Henry J. Kaiser Family Foundation, The Ford Foundation, The John D. and Catherine T. MacArthur Foundation, the Charles Stewart Mott Foundation, The McKnight Foundation, The Commonwealth Fund, the Stuart Foundation, the Weingart Foundation, The Fund for New Jersey, The Lynde and Harry Bradley Foundation, the Joyce Foundation, and The Rockefeller Foundation.

The nonpartisan Urban Institute publishes studies, reports, and books on timely topics worthy of public consideration. The views expressed are those of the authors and should not be attributed to the Urban Institute, its trustees, or its funders.

The authors would like to thank the many state and local officials who participated in our study and provided valuable insights into their experiences designing and implementing SCHIP. In particular, we are indebted to the SCHIP and Medicaid directors (and their staffs) of our 18 study states, who were instrumental in helping us plan our site visits, provided significant background information, and gave generously of their time by participating in our interviews.

At the Urban Institute, we would like to thank our colleagues for their input and suggestions on this report, including Lisa Dubay, Genevieve Kenney, John Holahan, and Alan Weil.

Finally, we would like to express our gratitude to the various funders that supported this effort, including the Robert Wood Johnson Foundation, the David and Lucile Packard Foundation, and the March of Dimes.

About the Series

Assessing the New Federalism is a multiyear Urban Institute project designed to analyze the devolution of responsibility for social programs from the federal government to the states, focusing primarily on health care, income security, employment and training programs, and social services. Researchers monitor program changes and fiscal developments. In collaboration with Child Trends, the project studies changes in family well-being. The project aims to provide timely, nonpartisan information to inform public debate and to help state and local decisionmakers carry out their new responsibilities more effectively.

Key components of the project include a household survey, studies of policies in 13 states, and a database with information on all states and the District of Columbia, available at the Urban Institute's Web site (http://www.urban.org). This paper is one in a series of occasional papers analyzing information from these and other sources.

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Executive Summary

Study Background and Purpose

Although the primary goal of the State Children's Health Insurance Program (SCHIP) is to extend health insurance coverage to the estimated 10 million uninsured low-income children in America, SCHIP also presents an opportunity to insure one of our nation's most vulnerable groups: children with special health care needs (CSHCN). Recent research has revealed that children with disabilities and chronic illnesses may make up 17 percent of low-income uninsured children, or roughly one of every six children eligible under SCHIP (Newacheck et al. 1998).

Understanding the implications of this potentially high prevalence of CSHCN is important given the large variety of SCHIP programs implemented in the last three years—roughly two-thirds of the states have used the flexibility in the law to design and implement new child health insurance programs, either separately or in combination with Medicaid expansions (Health Care Financing Administration 2000).

Therefore, even at this early stage of implementation, it is reasonable to ask how, or how well, SCHIP will respond to the needs of children with chronic illnesses and disabilities. This study begins to answer this question, based on a qualitative analysis of the implementation experiences of an 18-state sample.

Key Findings

The findings from this study suggest that most states did not focus particular attention on CSHCN during SCHIP program development. Rather, policymakers grappled with the broader issues of designing the most promising programs for insuring large numbers of children and determining whether this would be better accomplished through Medicaid expansion or separate programs. As a result, states have typically enrolled CSHCN into the same systems of care used by the general SCHIP population and subjected these children and their families to the same rules and policies as all other children. In a small but significant number of separate programs, however, special initiatives have been designed that attempt to address the special needs of children with disabilities and to provide more "Medicaid-like" coverage; these efforts tend to reduce the potential differences between Medicaid and separate programs.

A more specific aim of this study was to discern how, and to what degree, SCHIP programs have responded to the needs of CSHCN by designing special programs and policies. Key findings are summarized below.

- ***Outreach, Enrollment, and Identification.*** In none of the study states' SCHIP marketing campaigns did we see any overt efforts to reach out to CSHCN and their families and target them for enrollment. Rather, states focused on much broader campaigns to raise the general public's awareness of SCHIP and on efforts to simplify eligibility rules and processes. Furthermore, the few states that have implemented systematic processes for identifying CSHCN among all the children that enroll in SCHIP have had limited success with these efforts. A number of states did, however, describe efforts within their Title V/CSHCN programs to inform families with uninsured children, and their doctors, of the availability of coverage.

- ***Benefits.*** Not surprisingly, benefit packages under separate programs were found to be more limited than those covered by Medicaid. However, coverage in separate programs is quite broad, and was often described as "much better" than typical private coverage. Although policymakers could not identify cases in which children needed benefits that were not covered, many of the services often needed by CSHCN are precisely those that are either omitted or subject to limits under SCHIP, including case management, nonemergency transportation, rehabilitative therapies, and behavioral health services. Of special interest, two of the states we studied—Connecticut and North Carolina—have designed "wrap-around" benefit packages for CSHCN to supplement the basic coverage available to all children and to extend more open-ended Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT)-equivalent coverage to CSHCN in separate programs.

- ***Service Delivery.*** In almost every state, SCHIP programs are relying on managed care and CSHCN are being served through the same systems of care that serve all children. Typically, no special provisions are made to help ensure that appropriate access is extended to CSHCN in these arrangements. Although this may create reason for concern, key informants interviewed during our site visits, including family advocates, could report few or no cases in which delivery systems seemed to be failing to meet the needs of CSHCN. Furthermore, in California, Florida, and Michigan, specialized "carve-out" or managed care systems for SCHIP-enrolled CSHCN have been tailored to include the providers and supports that CSHCN and their families so often need. Early experiences suggest that these systems offer significant potential to provide more comprehensive and coordinated care for CSHCN than mainstream managed care systems.

- ***Cost Sharing.*** SCHIP has granted states considerable new flexibility to impose cost sharing—in the form of premiums and copayments—on eligible families. Given the likelihood that they will consume services at rates greater than the norm, CSHCN and their families are particularly vulnerable to high out-of-pocket costs as a result of copayment policies, and only three of the study states reported policies that exempted CSHCN from cost sharing or that somehow protected them from undue expense. However, Title XXI protects any family

from spending more than 5 percent of its income for SCHIP coverage, and early impressions are that cost-sharing amounts under SCHIP are nominal and affordable. Indeed, they were often referred to as "much lower" than those found in private insurance policies.

- ***Crowd-Out Waiting Periods.*** During its design phase, concern over SCHIP's potential to substitute for private-sector health insurance coverage was widespread among state legislators. As a result, most states now impose "waiting periods" of various lengths, during which families must be uninsured before being permitted to enroll, to discourage them from dropping existing coverage to sign up for SCHIP. SCHIP officials and family advocates reported that these waiting periods might disproportionately affect families of CSHCN—because they are more likely to be "underinsured" for their child's condition (i.e., covered by limited or expensive policies), because SCHIP may offer a broader and more affordable alternative to their current coverage, and because they cannot risk dropping their current coverage for even a short period because of their children's needs. Six states, however, exempt families from waiting periods if their current coverage is posing a significant financial burden, and one state explicitly exempts families with CSHCN from any waiting periods.
- ***Prevalence of CSHCN among SCHIP Enrollees.*** For a variety of reasons, states have experienced difficulty identifying and enrolling large numbers of CSHCN into SCHIP programs, even those with special provisions designed to better serve the population. Only between 1 and 8 percent of SCHIP enrollees have been identified as having special needs among the five states that could report such data, far below national estimates.

Several possible explanations were offered for this last finding, including the lack of outreach targeted to CSHCN, ineffective identification systems, and the fact that SCHIP programs are still quite new and, perhaps, unknown among this group. It was also suggested, however, that rates of uninsurance among CSHCN may be lower than those presented in the research literature. Furthermore, for those families whose CSHCN are insured, coverage that is expensive or limited in terms of a child's special needs condition may be creating a problem of underinsurance. For these families, waiting-period policies designed to discourage or prevent crowd out may be posing a particular barrier, which raises a critical question, and challenge, for the Title XXI program: Although primarily designed to extend health insurance to uninsured children, can SCHIP also be amended to address the needs of *underinsured* children?

In the interest of equity, policymakers might consider two changes in current policy that would allow the program to address the needs of the underinsured:

1. ***Permit SCHIP coverage to "wrap around" existing private health insurance for selected priority populations, such as children with special health care needs.*** The Medicaid program has always been permitted to wrap around private coverage. Federal policy states that Medicaid is to serve as the "payor of last resort" for dually insured persons, and much effort is made by state Medicaid administrators to coordinate benefits for such persons and ensure the integrity of the Medicaid system. Federal rules could be modified to allow Title XXI to play this same role by covering services above and beyond those covered by current private policies and, perhaps, by helping families to pay cost-sharing expenses. Such wraparound

coverage, if not extended to all privately insured children, might be targeted only to those with chronic illnesses and disabilities who are at risk for underinsurance. Such a change would not, in fact, represent an easing of federal and state crowd-out policies; in fact, it would reinforce that SCHIP coverage should not substitute for private coverage, but would permit the program to fill in gaps that might be present in that private coverage.

2. ***Encourage or require states to broaden their waiting period exceptions policies to allow children with special health care needs to drop private coverage if that coverage is deemed significantly limited or expensive.*** This policy change would expand what is already occurring in a handful of states, where exceptions to waiting periods acknowledge that some families' private coverage, while creditable, may be very expensive or limited and, therefore, that children with such coverage should be permitted to switch to SCHIP.

This study provides preliminary evidence that SCHIP programs appear to be providing relatively broad and affordable coverage to low-income children, including children with special health care needs. It has also revealed that an encouraging number of states have implemented special provisions—in the areas of benefits coverage, service delivery design, and crowd-out prevention—to make SCHIP more responsive to the needs of CSHCN and their families. As programs mature, it is reasonable for policymakers to consider possible amendments to Title XXI, such as those suggested above, that might improve the program's ability to serve the various subgroups of children who are particularly vulnerable.

Are We Responding to Their Needs? States' Early Experiences Serving Children with Special Health Care Needs under SCHIP

Introduction

The Balanced Budget Act of 1997 created Title XXI—the State Children's Health Insurance Program (SCHIP)—to achieve the broad goal of extending health insurance coverage to the estimated 10 million low-income children in America who lacked it. The law did not, however, expressly identify any subgroups of children who should receive priority consideration as states expanded coverage, beyond targeting children living in families with incomes below 200 percent of the federal poverty level (FPL). In particular, no priority was given to identifying and enrolling uninsured children with disabilities or chronic illnesses. Interestingly, recent analysis has shown that children with special health care needs may in fact make up a significant proportion of those who are uninsured: It has been estimated that 17 percent of low-income uninsured children have a special health care need, representing roughly one of every six children made eligible for new health insurance coverage under SCHIP. Of these children, nearly 40 percent have a chronic condition that is disabling, as defined by a limitation in school or play activities (Newacheck et al. 1998).[1]

Understanding the implications of this potentially high prevalence of children with special health care needs (CSHCN) is important given the large variety of SCHIP programs that have resulted in the three years after its implementation. Title XXI is noteworthy for the considerable flexibility it extends to the states in designing their children's health insurance initiatives. In general, it permits states to expand coverage through either Medicaid, the creation of a separate health insurance program, or a combination of the two approaches. More specifically, while states expanding coverage through Medicaid are largely held to that program's rules, states creating new programs have the freedom, within certain federal limits, to design new benefit packages and service delivery arrangements, impose cost sharing, adopt simpler eligibility rules and processes, and avoid the entitlement obligation of Medicaid by creating enrollment or budget caps, if they desire. Today, three years after the passage of Title XXI, every state (and the District of Columbia) has a SCHIP program up and running, with 18 states adopting Medicaid expansions, 15 implementing separate programs, and 18 choosing a combination approach (Health Care Financing Administration [HCFA] 2000). While this split appears quite even on its surface, in reality the Medicaid portion of most combined programs has been relatively small in terms of the population covered, and new programs have received much greater emphasis during states' design and implementation phases (Hill 2000). From this perspective, therefore, roughly two-thirds of the states can be viewed as having primarily focused their SCHIP initiatives on design-

ing and implementing new child health insurance programs, either separately or in combination with Medicaid expansions.

Together, the potentially high prevalence of CSHCN and the large number of new programs being implemented under SCHIP raise numerous questions regarding how, and how well, SCHIP will respond to the needs of children with chronic illnesses and disabilities. Particular questions of critical importance include the following:

- What will be the prevalence of CSHCN among children who enroll in SCHIP?
- Will outreach and enrollment initiatives incorporate any special efforts to reach and identify this group of children?
- Will benefits covered under separate SCHIP programs meet the multiple and complex needs of CSHCN?
- Will service delivery and payment arrangements be structured to include the range of providers needed by CSHCN and the financial incentives to promote their appropriate care?
- Will cost-sharing provisions have a disproportionate effect on CSHCN and their families, given their higher rates of service use?
- Will efforts to deter "crowd out," or the substitution of SCHIP for existing private coverage, adversely or disproportionately affect families with CSHCN, who may already possess expensive or limited insurance?
- Overall, how will newly created separate programs compare to Medicaid in addressing the needs of CSHCN and their families?

This study begins to answer these questions by analyzing the implementation experiences of a sample of 18 states, as described below.

Study Methods and Paper Organization

This study was conducted as part of the Urban Institute's *Assessing the New Federalism* project and, more specifically, its evaluation of the effects and implementation of SCHIP.[2] The qualitative component of the Institute's SCHIP evaluation involved the conduct of site visits of four to five days in length to 12 states and telephone interviews with 3 additional states, selected based on their diversity in size, population characteristics, geographic location, and SCHIP policies.[3]

For another study, we conducted site visits to five states—California, Connecticut, Florida, North Carolina, and Pennsylvania—chosen because they had focused particular policy emphasis on strategies for serving CSHCN under SCHIP. We conducted interviews with a broader array of providers specializing in serving this population, including both physical and behavioral health systems. We also conducted focus groups of parents of CSHCN.[4] A report summarizing the results of this previous study was published last year (Schwalberg, Hill, and Mathis 2000). In total, 18 states were studied; the study states are listed below.

SCHIP Study States

Alabama	Michigan	North Carolina
California	Minnesota	Ohio
Colorado	Mississippi	Pennsylvania
Connecticut	Missouri	Texas
Florida	New Jersey	Washington
Massachusetts	New York	Wisconsin

In the site visits and interviews, we spoke with a broad range of key informants. At the state level, we interviewed SCHIP, Medicaid, and Title V/Maternal and Child Health officials, governors' health policy staff, state legislators involved with child health policy, representatives of provider groups (such as the American Academy of Pediatrics and the primary care association), and leading child advocacy organizations. At the local level, we interviewed clinic- and office-based pediatric providers, managed care organizations (MCOs), social services departments responsible for SCHIP and/or Medicaid eligibility determination, and community-based organizations involved with outreach. To ensure the consistency of information gathered across sites, we used detailed interview protocols to explore a broad range of implementation issues, including outreach and enrollment strategies, benefit package design, service delivery arrangements, cost-sharing policies, and crowd-out prevention efforts, among others. Of particular note, we also explored with states the extent to which policies in any of these areas had been tailored to better meet the needs of CSHCN enrolled in SCHIP.

With the support of the March of Dimes, this paper combines the findings from these two efforts to report on states' early experiences serving children with special health care needs under SCHIP. The analysis is primarily based on qualitative data collected during site visits and telephone interviews from these 18 states. The upcoming sections are organized as follows:

- "Children with Special Health Care Needs—Who Are They? How Many Are There?" provides background information on children with chronic illnesses and disabilities, their prevalence, insurance status, and service needs, and the implications these characteristics hold for service delivery systems.
- "State Experiences Serving CSHCN under SCHIP" describes how and why the study states designed their SCHIP programs as they did, and discusses states' experiences implementing SCHIP and serving CSHCN. This discussion addresses the policy areas of outreach and identification, benefits coverage, service delivery and payment arrangements, cost sharing, crowd-out prevention, and prevalence of CSHCN. Where appropriate, this section highlights innovative provisions specially designed to be more responsive to the needs of CSHCN.

- The final section, "Conclusions and Implications for Future Policy," draws conclusions from the preceding analysis and discusses the implications for future policy of states' experiences to date serving CSHCN under SCHIP.

Children with Special Health Care Needs—Who Are They? How Many Are There?

The population of "children with special health care needs" defies simple definition. Depending on the definition used, estimates of the prevalence of CSHCN among children generally vary tremendously. First, we know that an estimated 150,000 babies are born each year with birth defects—including heart and circulatory disorders, cleft lip and palate, spina bifida, Down syndrome, and phenylketonuria—accounting for just under 4 percent of all births in the United States (March of Dimes 2001). However, not all chronic or disabling conditions are present or identifiable at birth, so prevalence estimates based on observations of a cross section of all children can be much higher. For example:

- Applying a very broad definition of CSHCN to children generally—one that includes many common chronic conditions that may have only modest effect on children's lives (such as eczema and repeated ear infections)—yields a prevalence estimate that exceeds 30 percent (Newacheck et al. 1992).
- Using much narrower criteria that consider only conditions causing severe disability or need for personal assistance or assistive technology to carry out basic activities of daily living results in prevalence estimates as low as 2 to 3 percent of the child population (Newacheck et al. 1992).
- Using definitions that measure the behavioral consequences of a child's condition for physical, psychological, and social functioning, and the evidence of the need for services over and above the norm for children of a similar age, leads to estimates of prevalence in the 15 to 18 percent range (Stein, Westbrook, and Bauman 1993).
- In recent years, a consensus has begun to emerge supporting the definition developed by the federal Maternal and Child Health Bureau cited above—that CSHCN are those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally—which yields a prevalence estimate of 18 percent (McPherson 1998).

As these definitions imply, children with special health care needs are also difficult to categorize because they experience an incredibly diverse range of conditions, spanning physical, developmental, behavioral, and emotional domains. What's more, the severity with which any given child experiences any given condition can also vary significantly, from mild to moderate to severe. Finally, many CSHCN have multiple problems that affect multiple body systems.

These characteristics combine to inform us that CSHCN may often require access to a very diverse set of health care and other services. Children with special health care needs, like all children, benefit from access to a preventive and primary care "medical home." However, their conditions may also require that they receive specialty medical services, developmental services, habilitative and rehabilitative therapies, durable medical equipment and assistive technologies, and mental health services, among others. Given this constellation of care, CSHCN and their families can also particularly benefit from an array of support services, such as intensive care coordination or case management (to help them arrange and obtain services from multiple sources), family therapy (to help them cope with the stresses of having a disabled child or sibling), and respite care (to provide families with occasional breaks from the rigorous demands of caring for their disabled child). These diverse needs also mean that families with CSHCN must rely on a great many health care and other systems to receive their care. Any given child may, at various points, rely on not only the medical care system, but also systems providing early intervention, special education, mental health, and other equipment and supports. In general, we know that CSHCN average three times as many sick days and school absences as other children, more than twice as many physician contacts, and five times as many hospital days as children in general (Maternal and Child Health Bureau [MCHB] 2000).

With increased reliance on managed care in both public and private health insurance systems, many policymakers, analysts, and advocates have questioned whether managed care organizations possess the capacity to provide CSHCN with sufficient access to appropriate and high-quality care. Concerns have most often centered around (1) the breadth and adequacy of MCOs' networks, (2) financial incentives under capitated arrangements that may cause MCOs to avoid enrolling CSHCN or limit access to needed, but expensive services once CSHCN are enrolled, (3) MCOs' general lack of experience with the complex and diverse needs of these children, and (4) inadequate links between MCOs and the multiple health-related, educational, and community-based support systems that families with CSHCN rely on in caring for their children (Committee on Children with Disabilities 1998; Zimmerman et al. 1996; Cartland and Yudkowsky 1992). Others argue that managed care, at least in theory, holds the potential for improving the organization of care, as well as overall accountability, through the use of integrated provider networks. Recent research has also suggested that emerging specialized managed care systems within some state Medicaid programs, systems designed to address the needs of CSHCN in particular, show considerable promise for promoting more comprehensive, family-centered, and integrated approaches to serving these vulnerable children (Hill, Zimmerman et al. 1999).

Regardless of the system or systems used, the ability of CSHCN to access services is heavily dependent on their possessing health insurance. The good news is that, compared with the general population of children, CSHCN (using the MCHB definition) are slightly more likely to be insured—an estimated 89 percent have some form of health insurance (Newacheck et al. 2000). Slightly less than two-thirds of insured CSHCN have private coverage, while approximately 30 percent have public insurance, most often Medicaid by virtue of their eligibility for Supplemental Security Income (SSI) benefits or because they meet their state's "medically needy" eligibility criteria. A relatively small number of all CSHCN—roughly 860,000 nation-

ally—receive supplemental assistance in accessing health services from state Title V/Maternal and Child Health Programs (Maternal and Child Health Bureau 2000).[5]

For those without insurance, however, research has clearly shown that access to care is severely compromised, especially among the low-income uninsured. Low-income uninsured CSHCN are more than four times as likely to lack a usual source of care than their insured counterparts (22 vs. 5 percent); average about half as many physician contacts as similar children with insurance (5 vs. 11 contacts); and are almost three times as likely to have unmet health needs as insured CSHCN (35 vs. 13 percent) (Newacheck et al. 1998).

However, simply possessing insurance does not necessarily mean that the needs of a chronically ill or disabled child are adequately met—while insured CSHCN clearly have better access than those who are uninsured, the problem of "underinsurance" among families with CSHCN with private coverage is reportedly quite common (Hill, Schwalberg et al. 1999). Underinsurance generally refers to a situation in which families possess coverage that is expensive to use or limited in scope, and therefore does not fully meet their needs. For CSHCN, this problem can be particularly relevant, because of the common private insurance practice of placing annual or lifetime limits on the coverage of various services and because of the higher-than-normal out-of-pocket costs these families sometimes face in the form of premiums, deductibles, coinsurance, and copayments. Few studies have attempted to directly measure underinsurance, but a recent national survey of parents of CSHCN found that (1) 21 percent paid more than $3,000 per year out-of-pocket for services not covered by their children's health insurance, (2) 56 percent reported financial impact resulting from their children's health condition, and (3) financial impact was more likely to be reported by parents whose children's primary insurance was private (usually employer-based) rather than Medicaid (Krauss et al. 2000). This survey also found that fully 40 percent of CSHCN also possessed secondary health plan coverage and that the vast majority of this secondary coverage was public in nature, usually Medicaid wrapping around private health insurance (Krauss et al. 2000). Although not specific to children, another study estimated that, among all privately insured persons under age 65, 18.9 percent would be underinsured if faced with a catastrophic illness (Short and Banthin 1995). This underinsurance rate rises dramatically for individuals in poor health—34.7 percent—and individuals with low incomes—61.6 percent of those with incomes below 125 percent of the FPL (Short and Banthin 1995).

In light of these facts, the potential for SCHIP to assist uninsured CSHCN and their families is enormous. Yet states' ability to take best advantage of this opportunity will depend on many factors related to how individual state SCHIP programs are designed and implemented. To adequately serve this population, benefits must be sufficiently broad, service delivery networks must include the necessary array of providers, payment arrangements must encourage (or at least not discourage) comprehensive care, and cost sharing must be affordable. In addition, the nature of states' efforts to deter the substitution of SCHIP for existing private insurance—so-called crowd-out prevention—may dramatically affect the extent to which an

underinsured child with special needs will be able to access new coverage offered by Title XXI.

State Experiences Serving CSHCN under SCHIP

This section provides a detailed analysis of the designs of 18 state SCHIP programs and their experiences to date serving CSHCN. The analysis first summarizes the policy debates that occurred in the states and the degree to which this population was a focal point of discussion. Following this, six key policy areas are discussed, including outreach and identification, benefits coverage, service delivery and payment arrangements, cost sharing, crowd-out prevention, and prevalence of CSHCN among SCHIP enrollees.

The Policy Debate—Were CSHCN a Consideration during Program Design?

The State Children's Health Insurance Program offered states a unique opportunity to expand health coverage for children, and every state took advantage of this opportunity within just over two years (Ullman, Hill, and Almeida 1999). Among the 18 states included in this study, a common set of factors was cited by key informants as fueling a rapid response, including the availability of enhanced federal matching funds (with states responsible for just 70 percent of the share they pay for Medicaid), bipartisan support for children's insurance expansions, and strong state economies (Hill 2000).

The topic that dominated discussion during most states' design phase was the broad question of whether to use SCHIP authority to expand Medicaid or to create a new program. As noted above, two-thirds of all states (and 14 of the 18 states in this study) concluded that SCHIP should be used to test alternatives to Medicaid. Several common reasons were given for this move, including political resistance to expansion of a federal entitlement program, legislative objection to fueling further growth in Medicaid, and a perception that access-to-care problems under Medicaid were too severe and that further expansion of Medicaid would simply exacerbate the situation. Perhaps most prevalent was policymakers' expressed desire to create programs that resembled private insurance and were free of the welfare-related stigma that was perceived as pervasive among both consumers and providers of care under Medicaid (Hill 2000).

Notably absent from this larger debate was discussion of how different design choices might affect children with special health care needs. In the majority of states in this study, CSHCN were "not even on the radar screen," as policymakers focused on the broader issue of how best to extend health insurance to children in general.

In a handful of states, however, the CSHCN population did manage to receive attention and particular provisions were made to specifically address their needs under SCHIP. These instances are described below.

- In Connecticut, the very first meetings to discuss SCHIP included not only governor's staff and officials from the state Medicaid agency, but also leading child advocates. From the start, it was clear that executive branch leadership would not support a Medicaid expansion and that the state employees' benefit package would offer a more "mainstream" coverage model. However, it was also widely acknowledged that this package might not provide adequate coverage for CSHCN, so plans to supplement the "basic" package with a set of enhanced benefits emerged. This "wraparound" coverage would eventually take shape as *HUSKY Plus*, the parameters of which are discussed in more detail in the next section.
- In North Carolina, the director of the Children's Special Health Services Program (the CSHCN component of the state's Title V/Maternal and Child Health Block Grant program) served as cochair of the public/private task force appointed by the Secretary of the Department of Health and Human Services to plan the state's SCHIP program. This individual, a long-standing and well-respected public servant, succeeded in keeping CSHCN among tne issues being considered as the task force weighed the merits of alternative program designs. When, ultimately, a separate program was selected and designed after the state employees health plan—called *Health Choice*—the task force succeeded in receiving authorization for coverage of additional Medicaid-equivalent physical, developmental, and mental health benefits for CSCHN, supported by funds earmarked for this purpose.
- In Alabama, state planners also opted to create a separate program—*All Kids*—using the benchmark benefit package offered by the health maintenance organization with the largest insured commercial, non-Medicaid enrollment in the state, delivered through the state's large Blue Cross/Blue Shield network. During the planning phase, this group also agreed, in concept, to the creation in year two of a supplemental program—*All Kids Plus*—for CSHCN with needs beyond those met by the basic package.

In four additional states—California, Florida, Massachusetts, and Michigan—special initiatives for CSHCN enrolled in Medicaid were already in place before the passage of Title XXI. In these states, it was decided that these special models should be incorporated into SCHIP so that CSHCN covered by Title XXI would have the same opportunity to receive specialized services as their counterparts in Medicaid. Specifically:

- In California, the Title V/California Children's Services (CCS) program had, over the years, established a broad network of primary, specialty, and ancillary providers to serve CSHCN enrolled in the state's Title V program. With the roll-out of Medicaid managed care during the 1990s, it was decided that specialty care for CCS-eligible children enrolled in Medi-Cal would be "carved out" of the responsibilities of managed care providers and delivered through the separate CCS system. This carve-out arrangement was extended under SCHIP for children enrolled in *Healthy Families* who had CCS-eligible conditions.
- In Florida, a special managed care system designed specifically for CSHCN had been implemented as part of the state's Medicaid managed care program in

1996. This Children's Medical Services (CMS) Network, administered by the state Title V program, was also incorporated into *KidCare* as one of the service delivery options extended to CSHCN enrolling in SCHIP.

- In Massachusetts, the previously state-funded CommonHealth program for CSHCN was federalized under Title XXI and incorporated as a component of the state's *MassHealth* program. Children with special needs enrolled in *MassHealth* are provided access to a broader benefit package than other enrollees, one that is essentially equivalent to Medicaid except that it does not cover long-term care.
- Michigan's special managed care system for CSHCN—the Special Health Plan—was implemented as part of the state's Title V/CSHCN program in 1998 and made available to CSHCN who also had Medicaid. The Special Health Plan offered such children the option of receiving services through capitated networks specifically crafted to meet their needs. Again, this option was carried forth under SCHIP such that CSHCN in Michigan's Title V program who are also enrolled in *MIChild* are able to receive services through this special service delivery option.

Thus, overall, 7 of the 18 states included in this study can be considered to have made special provision for CSHCN during the design phase of SCHIP. However, as five of these states were specifically selected for the study at least in part because of their special initiatives for CSHCN, it is unlikely that this same proportion could be generalized to all 50 states.

Outreach, Enrollment, and Identification

Since the passage of Title XXI, outreach and enrollment issues have dominated federal and state policy agendas. Spurred in part by the very large commitment of federal dollars to the cause—approximately $40 billion over 10 years—expectations for SCHIP to dramatically reduce uninsurance among children ran high after the law's passage, and much of the attention since has focused on addressing why the program has not made greater inroads in insuring the estimated 10 million children who lack health coverage. Indeed, recent research has found that, in most states, unprecedented time, energy, and resources have been committed to SCHIP outreach and simplifying the enrollment process. Marketing efforts have generally involved statewide mass media campaigns and community-based strategies, and programs have worked to avoid overt associations with government, instead using bright and colorful images and messages, as well as new names, such as *Child Health Plus* (New York), *KidCare* (Florida), *MIChild* (Michigan), *Health Choice* (in North Carolina), and *All Kids* (Alabama). It is noteworthy that outreach efforts have been accompanied by commensurate efforts to simplify and streamline the SCHIP eligibility process. The vast majority of states in this study (and nationally) have adopted some combination of strategies, including shortening their application forms, dropping assets tests, allowing applications to be submitted by mail, reducing the amount of verification that must be submitted with applications, and providing continuous 12-month eligibility to children (Westpfahl Lutzky and Hill in press; Perry et al. 2000; Cohen-Ross and Cox 2000).

This study investigated whether any of these outreach or enrollment efforts were specially targeted toward CSHCN and their families. In short, we found none, even among the states that have designed special programs for CSHCN served by SCHIP. Rather, SCHIP marketing has been broadly cast, and the relatively few targeted efforts observed tended to be pointed toward various ethnic groups, including various Spanish-speaking and Asian groups. Furthermore, no special eligibility criteria or enrollment strategies were tailored for populations with disabilities (although this group, like all families, was expected to benefit from general simplification efforts).

In some ways, this finding should not be surprising. Some state officials explained that CSHCN and their families made up too small a group to justify an investment in specialized outreach. In addition, many officials explained that they chose, instead, to target outreach efforts to the providers likely to be in contact with CSHCN. For example, Florida state officials described explicit strategies by the CMS program to inform pediatric providers of SCHIP, an approach they thought more efficient for reaching this subset of children. Similarly, most states' Title V/CSHCN staff reported efforts to search their patient records, as well as records of leading children's hospitals, for uninsured children and to refer them, once found, to SCHIP. On the other hand, some officials also admitted that states may have been reluctant to overtly advertise SCHIP as a program for children with disabilities for fear of adverse selection (i.e., attracting a "sicker," more expensive pool of child enrollees).

We also queried SCHIP officials and other key informants about their systems for identifying CSHCN among those children being enrolled in SCHIP. Having this capacity is important because if a program expects to provide extra support or services to CSHCN and their families, it must first have the ability to identify these children, assess their needs, plan their care, and deliver a coordinated set of services through the systems established to address their special needs. This study reinforced previous research findings in that, even among the handful of states that have done the most work to tailor their programs for CSHCN, this fundamental step of identifying and enrolling them has proven quite challenging and problematic (Schwalberg, Hill, and Mathis 2000).

To some extent, this problem stems from the lack of consensus on a definition of CSHCN and the challenges involved in developing policies based on alternative definitions of the population. In the majority of study states, no attempt at all is made by program administrators to identify CSHCN—children with disabilities are served through the same systems as all other children and no special provision is made for addressing their needs. Thus, identification and care provision are left to clinicians and other providers, not program administrators.

In the seven states with special initiatives for this population, a variety of approaches have been tried to identify CSHCN, none of which were described as satisfactory or truly successful. For example:

- In Florida and Pennsylvania, the SCHIP application form includes a single question along the lines of, "Does your child have a special health care need, or medical or developmental condition expected to last more than 12 months?" An affirmative response triggers a referral to either a managed care case manager (in the case of Pennsylvania) or a Title V/Children's Medical Services nurse (in Florida)

for further assessment and diagnosis. Both of these states, however, have found that this approach "casts the net too broadly"—fully one-third to one-half of parents in these states have identified their children as having special needs, ranging from routine need for eyeglasses to treatment for life-threatening illnesses—resulting in often time-consuming and inefficient follow-up with large numbers of families.

At the time of this writing, however, Florida's CMS program, with the support of a federal Title V grant, was studying an alternative approach. Specifically, four different questions, or question sequences, are being tested with a sample of enrollees' parents in an attempt to develop a more discriminating and accurate method for identifying children who are eligible for the CMS system.

- In North Carolina, the state's SCHIP application originally contained no screening question. Rather, all enrollees were given a ***Health Choice Handbook***, which included, among many items, a five-question screening form designed to identify CSHCN. Patterned loosely after the Questionnaire for Identifying Children with Chronic Conditions (QuiCCC) (Stein et al. 1997), this screen is quite broad and allows parents of children with birth defects, developmental disabilities, mental health problems, and other chronic conditions to identify their children as CSHCN and then call the state's toll-free Special Needs Helpline to learn about additional services and supports available.

  During the first two years of *Health Choice*, the state was not able to determine how consistently this approach succeeded in identifying large numbers of CSHCN. As a result, state officials were designing, at the time of this writing, a new application form that incorporates a five-question sequence (based on a tool developed by the Foundation for Accountability—FACCT) that they hope will better identify CSHCN. With this application design, parents who answer "yes" to any of the five questions will have a special field identified in their program eligibility record. This field allows the state to both track the prevalence of special needs among SCHIP (and Medicaid) enrollees and identify children who require special follow-up by SCHIP and Title V staff to ensure that their service needs are being addressed.

- In Alabama, California, Connecticut, and Michigan, SCHIP and Medicaid programs primarily rely on care providers, including primary and specialty care physicians and local health department nurses, to identify CSHCN and refer them to specialized care systems. Neither state program officials nor enrollment broker staff directly query families about the special needs of their children during the health plan selection process—such discussion is explicitly avoided because, it is reasoned, families might be reluctant to discuss their children's health status in the context of selecting a health plan, due to fear of discrimination or denial of choice.

Benefit Coverage

After the passage of the Balanced Budget Act of 1997, one of the most oft-cited advantages of adopting a Medicaid expansion under Title XXI was that Medicaid extends to children the broadest possible benefits coverage and virtually open-ended

protection under the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) provisions of the statute (Center for Health Policy Research 1997; Mann 1997; Weil 1997).[6] Similarly, one of the observed potential weaknesses of taking the separate-program route was the possible adoption of more limited benefit packages that might not fully meet children's needs. These issues are particularly salient for CSHCN, whose advocates found the prevailing arguments in favor of expanding Medicaid particularly persuasive.

A detailed analysis of the benefits packages of the new SCHIP programs included in this study reveals, however, that the worst fears of advocates—that separate programs might adopt severely limited benefits packages—have not materialized. Rather, states have typically adopted rich benefits packages that, while not the equal of EPSDT, are quite broad and "better than most private plans," according to key informants ranging from SCHIP program administrators to pediatricians, private insurers, and child advocates (Hill 2000; Hill forthcoming).

More specifically, among the 14 study states with separate programs, 6 adopted packages based on their state employees benefit package, 3 adopted packages based on that offered by the HMO with the largest enrollment in the state, 2 adopted packages based on the Federal Employee Health Benefit Package, and 3 had programs that predated SCHIP and had their benefits packaged grandfathered into Title XXI. These packages typically covered preventive well-child care, physician services, inpatient and outpatient hospital care, prescription drugs, and laboratory and radiological services. Furthermore, most of these states explicitly augmented these benchmark packages by adding coverage of services described as "critical for children," including vision, dental, and hearing services (California, New York, Connecticut, and North Carolina), mental health and substance abuse services (Florida and Pennsylvania), and durable medical equipment and rehabilitative therapies (Pennsylvania). Several states also adopted the periodicity schedules for well-child care endorsed by the American Academy of Pediatrics (Alabama, California, Florida, Michigan, and New York). North Carolina's separate program was actually described as having more explicit coverage than Medicaid of such services as cochlear implants, eyeglasses, and emergency respite care. In addition, at the time of this writing, the state had a special initiative underway to design comprehensive case management services for its *Health Choice* program.

Still, core benefit packages adopted for the general population of children under new SCHIP programs typically place limits on, or do not cover at all, many services that are particularly important to CSHCN and their families. For example, as shown in table 1, the separate non-Medicaid programs included in this study often place limits on ancillary therapies, home health care, mental health and substance abuse services, durable medical equipment, and assistive technologies. Some of these programs completely omitted coverage of such services as nonemergency transportation, case management, and other enabling services—again, services that can be critical to people with disabilities.

These gaps and limits in coverage call into question the ability of separate programs to comprehensively meet the needs of CSHCN. However, when asked if they had heard of any instances where children needed care but were unable to receive it

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due to coverage limits, key informants interviewed for this study could identify no such cases. This could possibly be explained by the fact that SCHIP programs were all quite new at the time of this study—with implementation experience of typically two years or less—or by the possibility that quality assurance and appeals procedures within states' service delivery systems, also new, were not yet effectively operational. However, even advocates for CSHCN and state legislators (who are often quick to hear of problems among their constituents) could not cite examples in which coverage problems had so far arisen. On the other hand, this finding might also speak to the health status of children who have enrolled in SCHIP, to date, or the extent to which current coverage policies may be successfully meeting the needs of the large majority of early enrollees.

Table 1. *Core Benefits Affecting Children with Special Health Care Needs in Non-Medicaid SCHIP Programs*

State	OT/PT/ST[a]	Durable Medical Equipment[b]/Supplies	Home Health	Case Management	Non-Emergency Transportation	Mental Health Inpatient; Outpatient	Substance Abuse Inpatient; Outpatient
AL	If condition improves	Unlimited	60 visits	Unlimited	Unlimited	30 days/year; 20 visits/year	72 hours/episode up to 20 days/year; 20 visits/year
CA	60 days	Excludes therapeutic footwear/diabetic supplies covered	Unlimited	Unlimited	Unlimited	30 visits/year; 20 visits/year	Detoxification; 20 visits/year
CO	30 visits/year	$2,000/year limit/diabetic supplies **not covered**	Unlimited	**Not covered**	**Not covered**	45 days/year; 20 days/year	Unlimited; 20 visits/year
CT	Unlimited	Unlimited	Unlimited	**Not covered**	**Not covered**	60 days/eligibility period; 30 days/eligibility period	60 days for drug abuse, 45 days for alcohol abuse/ eligibility period; 60 visits/ eligibility period
FL	24 visits,60 days	Unlimited	Unlimited	**Not covered**	**Not covered**	30 days/contract year; 40 days/contract year	37 days/year; 40 visits/year
MA	90 days; no limits if under age 3	Excludes eyeglasses, hearing aids and therapeutic footwear; diabetic supplies covered	Unlimited	**Not covered**	Unlimited	Unlimited if medically necessary	30 days/year cap rehab, unlimited detox; 20 visits/year
MI	Unlimited	Unlimited	120 visits/year	Only for mental health conditions	**Not covered**	Excluded: non-Medicaid benefits	Unlimited
MS	Unlimited	Unlimited/some limits on disposable supplies	$10,000/year with prior approval	Provided by carrier	**Not covered**	30 days/year; 52 days/year	$8,000/benefit period; $16,000 per lifetime and outpatient
NJ	60 visits/year	Unlimited	Unlimited	Covered when medically necessary	Invalid coach transportation	Unlimited	Unlimited
NY	PT and OT short term	Commodes, walkers, diabetics, and wheelchairs covered/diabetic supplies covered	Minimum 40 visits/year	**Not covered**	**Not covered**	30 days/year; 60 visits/year	30 days/year; 60 visits/year
NC	Unlimited	Unlimited	Minimum 60 visits/year	Unlimited	**Not covered**	Unlimited; 26 visits/year	Per authorization of case manager; 26 visits/year
PA	60 days	Unlimited	Unlimited	Only for mental health conditions	**Not covered**	Unlimited	Unlimited
TX	Unlimited	$20,000/year cap for DME and disposable supplies (diabetic supplies and equipment not counted against cap)	Unlimited	Unlimited	**Optional**	45 days/year; 60 visits/year	Detox/crisis stabilization 14 days/year, 60 days for partial hospitalization; 12-week limit for rehab
WA	Unlimited	Unlimited	Unlimited	Unlimited	Unlimited	Unlimited; 26 visits/year	3 days alcohol detox, 5 days for other drugs, unlimited for youths, 6 months treatment for women; 150 hours every 2 years except for the methadone program and pregnant, postpartum, and parenting women

Sources: State Children's Health Insurance Program 1999 Annual Report, National Governors Association and National Conference of State Legislatures.

Notes:

a. OT = occupational therapy, PT = physical therapy, ST = speech therapy.

b. DME = durable medical equipment.

c. In Florida, service limits shown are those of the *Healthy Kids* component of KidCare, not the CMS or MediKids components, for which full Medicaid benefits are covered.

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Regardless, as mentioned in the previous section, there were, among our study states, a small number that carefully considered the needs of CSHCN during the design phase of their SCHIP programs and planned special provisions to better meet those needs. Two of these—Connecticut and North Carolina—specifically focused on benefit policies and created special protections in the form of wraparound coverage for CSHCN. These states' initiatives are described in detail below.

HUSKY Plus—Connecticut

Connecticut's Healthcare for Uninsured Kids and Youth *(HUSKY)* program offers a set of wraparound benefits for children with special health care needs through the *HUSKY Plus* program. *HUSKY Plus* offers additional physical health, behavioral health, and support services to children who have special needs or whose needs exceed the basic benefits covered under the *HUSKY* program, the intent being to provide services beyond those offered by *HUSKY B*—the state's separate SCHIP program—and to extend Medicaid-equivalent coverage to children with special needs. The *HUSKY Plus Physical* package, which was modeled after the state's Title V Children with Special Health Care Needs program, includes both clinical services not covered under *HUSKY B* and support services, including family support, advocacy, and care coordination. This supplemental coverage is, in theory, available to all children who meet the state's definition of CSHCN: "children who have chronic physical, developmental, behavioral, or emotional condition (biologic or acquired)...(who) also require health and related services (not educational and recreational) of a type and amount not usually required by children of the same age."

The *HUSKY Plus Behavioral* program offers a narrower set of "integrated community services" designed to supplement the behavioral services covered under *HUSKY B*. These include intensive case management, in-home psychiatric and substance abuse treatment, and 24-hour mobile crisis services. These support services are provided in conjunction with the traditional inpatient and outpatient behavioral health services provided through the *HUSKY B* plans.

Under *HUSKY B*, services are provided through three contracted managed care plans. *HUSKY Plus* services, on the other hand, are administered by three contracted agencies, two for the *Physical* program (Connecticut Children's Medical Center in Hartford and Yale/New Haven Hospital in New Haven) and one for the *Behavioral* program (Yale/New Haven Hospital). Enrollees in the *Physical* program choose one of the two contractors to manage their care and provide support services; however, they continue to receive routine and specialty clinical services from their managed care plan and its community providers. The contractor for the *Behavioral* program works with a network of child guidance centers and hospital clinics organized in 10 regions throughout the state.

The managed care plans participating in *HUSKY A* (Medicaid) and *B* are paid on a per-member-per-month capitation basis. Under *HUSKY Plus*, however, the three contractors are allotted a set budget per year for administrative and clinical expenditures. A $5 million fund was divided equally between the *Physical* and *Behavioral* programs; in the *Physical* program, each center receives a budget to fund staff salaries, and a common pool is administered by one of the contractors for clinical services provided to enrollees in both centers. For the *Behavioral* program, the contractor administers the entire $2.5 million fund, from which it funds a portion of its directors' salaries and pays its subcontracting providers on a fee-for-service basis.

Access to both wraparound packages depends on identification and referral by the managed care plans in which children are enrolled; however, children can also be referred by their providers or parents. The state Department of Social Services has developed a referral form for plans and providers to use to identify children they suspect might be eligible for *Plus* coverage; this form requests only preliminary diagnostic information and does not include specific questions intended to identify children who meet the broad, functional definition outlined above. Rather, it is the *Plus* contractors who, upon receiving the referrals, conduct more in-depth diagnostic evaluations to determine whether children are eligible for *Plus* benefits.

During the first two years of implementation, the major challenge for the *HUSKY Plus* program appears to have been ensuring access to wraparound services for all of the CSHCN who might benefit. Health plan representatives whom we interviewed reported some confusion about the eligibility standards for *HUSKY Plus*, confusion that may have contributed to low rates of referrals to the wraparound program. Family support and care coordination staff in both *Plus* programs also suspected that plans and providers were conservative in making referrals to *Plus*, sending over only those children who had fully exhausted their core benefits and, thus, would be eligible for supplemental coverage. *Plus* providers felt strongly, however, that care coordination and family support services could be extremely useful to a broad range of children and families, whether or not they had exhausted the clinical services available through *HUSKY B*. Thus, while the *HUSKY* model includes many of the elements necessary for a comprehensive system of care for CSHCN, the challenges lie in their implementation.

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Wraparound Benefits for CSHCN in North Carolina

North Carolina's *Health Choice for Children* is a separate state program, based on the State Employees Health Plan, that uses a fee-for-service delivery and financing system. In addition to the basic benefits offered to all children, wraparound benefits are available to children with special health care needs. The program's basic benefit package includes the full range of medical benefits offered under the state employees' health plan, as well as dental, vision, and hearing benefits. However, this benefit package excludes certain types of durable medical equipment, such as hearing aids, chairs, and walkers; some nutrition therapies and special formulas; speech therapy for children with behavioral disorders; augmentative communication devices; and some assistive technologies. In addition, some behavioral benefits are excluded as well, including day treatment, high-risk intervention, and client behavioral interventions.

To remedy these omissions, a wraparound package was developed for children whose needs exceeded the limits of the basic benefit package. The intention of this additional package was to offer a level of benefits equivalent to that available through Medicaid; therefore, the services identified as being covered by Medicaid but excluded from *Health Choice*, such as those listed above, were included in the wraparound package. In addition, two support services were included that are *not* offered by Medicaid: emergency respite care and service coordination for children with chronic physical conditions and for those with mental health or substance abuse problems or developmental disabilities.

To identify children who may be eligible for these benefits, the state Division of Public Health created a five-item screening questionnaire that is sent to all enrollees with their insurance card. Parents are instructed to call a Special Needs Helpline if they answer "yes" to any of the five questions, which were designed to identify children with a broad range of conditions, including birth defects, developmental delays, behavioral problems, and chronic physical conditions.

Services under *Health Choice* are delivered through a statewide indemnity system for physical and mental health services. The State Employees Health Plan, through its contractor, Blue Cross/Blue Shield (BC/BS), administers benefits and processes physical health care claims under both the basic benefit package and the wraparound benefit. BC/BS, in turn, subcontracts with a behavioral health administrative service organization, Value Options, to provide utilization review for mental health and substance abuse benefits beyond those covered by the core package. The state's authorizing legislation specifically prohibits the development of a closed "provider network"; therefore, any licensed provider in the state may participate in *Health Choice*. Although this approach offers open access to any participating provider (reportedly including most primary care providers and specialists in the state), it has the drawback of not ensuring enrolled children a medical home, making it difficult to track and monitor the services used by any particular child.

All claims under the core benefit and the wraparound package are reimbursed on a fee-for-service basis, and neither BC/BS nor Value Options is at financial risk through the program. For the core benefit, funds are allocated to the State Employees Health Plan based on a per-child-per-month premium. In addition, a special $15 million fund was set aside to cover claims under the wraparound package. To date, the vast majority of claims for services for CSHCN have been approved for coverage under the basic benefit, as opposed to being debited against the special fund; under the program's financing structure, BC/BS has little incentive to shift costs from the basic benefit to the wraparound package.

In sum, it appears that CSHCN enrolled in *Health Choice* enjoy a comprehensive benefit package and have a wide array of health care providers to choose from. However, it is unclear whether the relatively low rate of use of the special fund for CSHCN is due to low rates of enrollment of this population, limited access to specialty services, or the incentives inherent in the program's fee-for-service payment system.

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Service Delivery and Payment Arrangements

In designing their SCHIP programs, state policymakers' first decision, as discussed above, was whether to expand Medicaid or establish a separate children's health program (or both). States that chose only to expand Medicaid would, of course, then use that program's provider networks or managed care systems to serve new enrollees. States that chose to develop separate programs, however, still faced the choice of using existing delivery systems developed by Medicaid or designing new provider networks to serve newly eligible children.

Indeed, this emerged as one of the more interesting issues in states with separate programs, with decisions regarding delivery systems often reflecting policymakers' relative level of confidence in Medicaid as well as their depth of knowledge of the state and local health care environment. In many states, for example, well-established Medicaid managed care systems, or a recent, well-received rollout of new Medicaid managed care initiatives, helped set the stage for SCHIP; in states such as California, Connecticut, Colorado, Massachusetts, and New York, SCHIP programs have contracted with most, if not all, of the same managed care plans that participate in Medicaid.

In other states, however, Medicaid did not enjoy the same level of acceptance among policymakers, providers, or the public, and thus support for the use of its service delivery infrastructure for SCHIP was undermined. Chronic problems with low provider participation or unsettled Medicaid managed care systems have combined to cause serious access problems in some states, leading policymakers to conclude that Medicaid delivery systems were too flawed to further build upon. In our sample, Alabama, Michigan, and Pennsylvania stand out as examples of states that set out to design entirely new SCHIP service delivery systems built around contracts with strong Blue Cross/Blue Shield organizations that enjoy significant penetration in the private health insurance markets.[7] SCHIP designers in these states saw particular advantage in the possibility of contracting with these organizations under SCHIP and extending more "mainstream" coverage to children enrolled in their new programs.

Following the example of both the private insurance market and an increasing number of state Medicaid programs, nearly all of the SCHIP programs in our study rely on managed care systems to pay for and deliver health care; among our sample of 18 states, Alabama and North Carolina are the only ones that rely primarily on fee-for-service models under SCHIP. Managed care was described as appealing to policymakers on several levels: It allows them to better predict program expenditures, and it can offer insurance coverage through private-sector systems that may more closely resemble private insurance than those of a public program. Thus, whether utilizing Medicaid delivery networks or not, most SCHIP programs have in common their use of managed care arrangements.

The decision by most states to use managed care systems under SCHIP can be seen as a reflection of policymakers' assumption, whether conscious or not, that managed care systems in their states possess the capacity to adequately serve all children, including those with chronic illnesses and disabilities. Indeed, as most states did not

focus significant attention on issues related to CSHCN during their program design phases, they have, by default, designed programs in which CSHCN receive their care through the same systems as all other children. However, once again, much controversy surrounds the issue of whether mainstream managed care systems have the experience and capacity to effectively serve CSHCN.

When asked whether their contracts with managed care plans contained any special provisions designed to safeguard CSHCN—such as provisions regarding the makeup of provider networks and requirements that they include specialty and other providers with expertise serving children with disabilities—the majority of SCHIP program administrators said the contracts did not. However, they also reported high levels of satisfaction with the breadth and depth of the plans with which they contracted and that they had heard of no cases, to date, in which SCHIP enrollees had not been able to access the care or services they needed. Once again, the relative youth of SCHIP programs at the time this study was conducted and the limited experience of plans in serving this population provide reasonable cause for accepting these initial positive findings with caution.

Ideally, state officials would systematically gather information that would allow them to analyze the appropriateness of the care provided to CSHCN under Medicaid and SCHIP programs. However, states' efforts to monitor and ensure the quality of care provided to CSHCN appear to be less consistent under SCHIP than under Medicaid managed care initiatives, and a recent federal initiative may widen this disparity. In response to provisions of the Balanced Budget Act of 1997, HCFA recently issued interim criteria for evaluating states' requests for waivers to enroll CSHCN in managed care under Medicaid.[8] These criteria include specifications that relate to the environment and program administration, purchasing strategy, access and quality, benefits and delivery system, breadth of provider networks, evaluation and reporting, financing, and other safeguards to ensure that managed care initiatives meet the full range of needs of CSHCN (HCFA 1998). However, these criteria do not apply to SCHIP programs and no discussion has yet occurred to suggest that they will. On the state level as well, this study found that states often subject Medicaid managed care plans to closer scrutiny than they do plans contracted under SCHIP; Connecticut's contracts with health plans, for example, require that they submit encounter data for their Medicaid enrollees but not for their SCHIP enrollees.

The use of managed care also raises issues regarding incentives inherent in capitated payment systems. In general, paying managed care organizations on a capitated basis provides an economic incentive to minimize or withhold services. For children with complex needs, this is particularly worrisome, as these children are the most likely to require costly care. Thus, states and researchers are working to develop methods for adjusting capitation rates to compensate plans appropriately for the care of CSHCN (Hwang, Ireys, and Anderson 2000). However, these methods are still in the developmental stages and among the states in this study, only Michigan was developing risk-adjusted rates to pay plans for the care of CSHCN under SCHIP.

Of note, four states in our study were not content to assume that mainstream systems would be sufficient to meet the challenges of serving CSHCN. These states, therefore, designed new, or adapted existing, service delivery arrangements to be

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more responsive to the needs of these children. The special service delivery arrangements established in Alabama, California, Florida, and Michigan are described in detail below.

All Kids Plus—Alabama

In order to better serve children with special health care needs, Alabama amended its SCHIP program, ***All Kids***, to include a special service delivery arrangement, ***All Kids Plus***. Essentially, ***All Kids Plus*** represents an expansion of the service delivery network available to children enrolled in SCHIP, achieved via a series of contracts between the Alabama Department of Public Health (the SCHIP lead agency) and three entities that historically have played a key role in serving CSHCN in the state: the Alabama Department of Mental Health and Mental Retardation (DMH/MR), the Alabama Department of Rehabilitation Services (DRS, which includes the Title V/CSHCN and Part C/Early Intervention programs), and the Sparks Center (a specialty clinic at the University of Alabama). Under the contracts, these agencies can now serve children enrolled in ***All Kids*** and receive enhanced federal matching funds as long as they agree to supply the state share of funding needed to support the required services.

Alabama attempts to identify children with special health care needs—so categorized based upon the definition used by the federal Maternal and Child Health Bureau—upon enrollment into ***All Kids***, through the use of a pediatric health questionnaire that is part of the program's application packet. Any child identified through this process is informed of and referred to an ***All Kids Plus*** provider. In addition, however, ***All Kids*** providers may identify children with special needs and refer them directly to ***All Kids Plus***. Finally, the ***All Kids Plus*** contracted providers may identify uninsured children among their patients and assist them with enrolling in ***All Kids*** (and, by extension, ***All Kids Plus***).

After a child is referred to an ***All Kids Plus*** provider, he or she is assigned a case manager who then develops a treatment plan and preauthorizes all needed services either within or outside of that setting. Although ***All Kids Plus*** does not represent a specified wraparound benefit package, it does identify and can authorize a range of services that it anticipates many CSHCN may need, including intake and evaluation; screening and assessment; case management; basic and adaptive living skills; counseling/testing/intervention; medical/surgical services; dental, vision, audiology and speech-language services; nutrition services; durable medical equipment; physical and occupation therapy; mental health and substance abuse services; in-home/community services (including respite, personal care attendant, homemaker/chore services, companion services, home health nurse, home health aide, behavioral aide, and transportation); special instruction/training; and social work services. These services must be provided by appropriately credentialed professionals.

All Kids Plus agencies bill Blue Cross/Blue Shield for all services provided, and reimbursement is adjusted to equal the actual costs that the agencies incur. The Alabama Department of Public Health then reimburses the insurance vendors in the same manner that they handle reimbursement for the basic ***All Kids*** program.

Alabama's approach is unique among those of the states included in this study. In essence, the program is a financing mechanism for providers and agencies that are already serving CSHCN with state-only funds. Enabling the receipt of enhanced federal matching funds is intended to permit these agencies and providers to significantly expand their capacity to serve CSHCN. With the increased revenue, these agencies are expected to, over time, either expand the range of services they provide or serve a larger number of children.

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The California Children's Services Carve-Out

California's ***Healthy Families*** program uses a carve-out approach to serving children with special health care needs. Children with chronic illnesses are enrolled in mainstream managed care plans for their primary and acute care, but receive the specialty services related to their conditions through California Children's Services (CCS) program, the state's Title V Children with Special Health Care Needs program. In addition, children who are diagnosed with serious emotional disturbance (SED) receive behavioral health services from county mental health departments (CMHDs). These carve-out arrangements replicate those in place under Medi-Cal, the California Medicaid program.

Healthy Families, the state's separate SCHIP program, covers children who have family incomes below 250 percent of the federal poverty level. All families, including those with CSHCN, apply for the program through a mail-in application form, and upon enrollment are asked to choose a managed health, vision, and dental plan for their children. The state agency that administers ***Healthy Families***, the Managed Risk Medical Insurance Board (MRMIB), requires that each participating health plan sign a Memorandum of Understanding with the CCS programs and mental health departments in their counties. These memoranda require that plan providers receive training in the CCS program's eligibility requirements—CCS services are available to children with certain medically handicapping conditions. If a pediatrician or specialist identifies a ***Healthy Families*** enrollee as having a condition that may qualify for CCS, a referral is made to the county's CCS program to determine the child's medical and financial eligibility. Similarly, children who are suspected of having SED are referred to the CMHD for an assessment of their SED eligibility.

Children who are eligible for CCS may receive a full range of specialty services ***for their CCS-eligible condition***, including diagnostic services, hospital and physician care, laboratory services, durable medical equipment, prescription drugs, home health, orthodontic services, HIV testing/monitoring, follow-up services for high-risk infants, and physical and occupational therapy. Limits on the ***Healthy Families*** benefit package (e.g., limits on therapy visits) do not apply to the CCS-eligible condition. The CCS program is responsible for authorizing and arranging for these specialty services, which are provided through CCS-certified, or "paneled," providers. While ***Healthy Families*** plans are not required to contract with the CCS-paneled providers in their counties, they are encouraged to do so; however, children may have to change specialists when they enroll in CCS. Behavioral health services for children diagnosed as SED are provided through the CMHDs. The policy goal of this carve-out benefit is to provide access to experts in children's mental health services through each county's publicly funded mental health program.

In any carve-out system, the major challenge is coordination between two systems of care. Although ***Healthy Families*** plans and county CCS agencies are required to have Memoranda of Understanding in place, state regulations do not spell out the degree or method of communication and coordination between the two systems. Thus, communication and information sharing between plans and CCS programs have been inconsistent and not based on formal protocols, we found. Coordination problems also appear to exist at the client level: Although the ***Healthy Families*** plans and CCS programs provide care coordinators to oversee the services their agencies provide, no single agency has responsibility for coordinating the full range of services that CSHCN receive. To address such issues, the state convenes quarterly meetings of "stakeholders" to identify problems and develop solutions.

Healthy Families plans are paid on a capitation basis. These capitation rates include primary care and specialty services not provided through the CCS program. Providers of carved-out specialty services are paid on a fee-for-service basis, using Medi-Cal's rate schedule. Because the plans receive capitated rates and are not responsible for specialty care for CCS conditions, their incentive is to refer as many enrollees as possible to CCS. This can cause problems for specialty providers, who may first have to receive a denial from CCS before they can bill ***Healthy Families*** plans.

California's carve-out approach has both advantages and disadvantages. CSHCN have relatively open access to qualified providers through the CCS program that they might not have had if they were limited to a commercial plan's network. In addition, children and families benefit from the CCS program's infrastructure of specialty physicians, clinics, and hospitals and the county mental health infrastructure available to serve SED children. However, California's complex managed care system, coupled with the county-based CCS and mental health systems, increases the potential for fragmentation of services and complicates the task of care coordination for CSHCN. The challenges presented by a county-based carve-out model call for strong state leadership and rigorous quality monitoring to assure that CSHCN have access to and receive high-quality, coordinated care.

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The Children's Medical Services Network—Florida

Florida's *KidCare* program encompasses four programs. In addition to Medicaid, the state has established three SCHIP components for different populations of children with family incomes under 200 percent of the federal poverty level: MediKids, a nonentitlement program offering Medicaid benefits to children under age 5; Healthy Kids, a separate state program for school-age children; and **Children's Medical Services (CMS)**, a specialty network providing primary and specialty services for children with special health care needs. Thus, Florida's approach represents a specialty managed care model of serving CSHCN under SCHIP. This model represents an extension of the approach in use for several years under Florida's Medicaid managed care initiative, which exempts Medicaid CSHCN from enrollment in the state's capitated HMOs and enrolls them in the CMS Network, which is operated by the state's Title V program. Under *KidCare*, the same system is used to serve CSHCN, but services are financed under a capitated rate rather than through fee-for-service payments.

The CMS Network, which operates independently in each region of the state, serves children who are found to have a functional disability or condition expected to last 12 months that requires extra or special medical care, therapies, supplies, or equipment. In addition, the state has also implemented the Behavioral Health Specialty Care Network (BHSCN), a pilot program for children with behavioral health care needs. This program, which is open to 300 children statewide, allows children with serious emotional disturbances (SED) to enroll in CMS and to receive an enhanced package of behavioral health services.

Most children who may be eligible for the CMS Network are initially identified through a question on the *KidCare* application form, asking whether the child has a medical or developmental condition that is expected to last at least 12 months. When an applicant checks "yes" to this question, the application is referred to the CMS office in the child's region. While the financial eligibility determination is being conducted by *KidCare*, the CMS case managers determine whether the child meets the CMS functional and diagnostic criteria. The BHSCN uses its own screening and assessment process to determine clinical eligibility. Because the screening question on the application form does not ask about mental or behavioral health needs, very few applications indicate a need for behavioral health care; most referrals for the pilot program are generated through CMS or through locally based outreach to providers. Once a referral has been made, a behavioral health assessment is completed. If the child is eligible for the BHSCN, the enrollment forms are forwarded to CMS.

The CMS Network provides children with the full Medicaid benefit package as well as other medically necessary services, including early intervention, respite, genetic testing, genetic and nutritional counseling, parent support, and care coordination. BHSCN provides all of the behavioral health benefits available to Medicaid enrollees as medically necessary, plus an assortment of enhancements such as individualized wraparound services, intensive case management, respite care, and other support services. No limits are placed on inpatient services, treatment planning, clinic visits, evaluation and testing services, day treatment, home and community rehabilitative services, or pharmaceutical services. In both of these benefit packages, comprehensive care coordination is critical for helping families to gain access to and manage the variety of services their children need.

CMS enrollees are served through a provider network—including primary care providers, specialists, hospitals, DME suppliers, and therapists—developed specifically for CMS through a credentialing process. The Behavioral Health Specialty Care Network allows the behavioral health care of children with the most severe mental health needs to be provided outside of the main CMS system, but CMS is the medical home for all BHSCN enrollees. Each district negotiates risk-bearing contracts with a lead agency, usually a community mental health center, which may in turn subcontract with other community-based providers to provide the full array of covered services.

All of the *KidCare* programs are funded on a capitated basis; however, the methodologies used to develop the rates and the rates themselves vary across the four programs. CMS receives age-adjusted monthly payments that range from 6 to 40 times the rates paid for children enrolled in Healthy Kids. These rates were developed based on historical CMS program expenditures under Medicaid. In the program's new capitated structure, risk is assumed by the CMS program at the state, rather than the regional, level.

The system of care for low-income children in Florida presents something of a paradox. On one hand, the system is complex from both an administrative and a consumer perspective. The use of four separate programs to cover children of different ages, income levels, and diagnoses has the potential to cause confusion among consumers, and creates a significant outreach and marketing challenge for state officials. However, use of a specialty system to serve CSHCN regardless of age or income, along with the state's history of developing state-level partnerships and local infrastructures through which to serve these children, has contributed to the establishment of an inclusive, comprehensive system for their care.

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MIChild Special Health Plans—Michigan

Michigan's *MIChild* program is a separate state SCHIP program modeled on the state employees health plan. Under this program, children with special health care needs may be served through the Children's Special Health Care Services (CSHCS) program, the state's Title V CSHCN program, if they choose to enroll in this program rather than a mainstream *MIChild* plan. Thus, this model represents a voluntary specialty system.

The CSHCS program offers two distinct delivery systems. In 35 counties, enrollees have the option to join one of two Special Health Plans that receive capitated payments to provide comprehensive care to CSHCN. Those who opt not to join a Special Health Plan and those who live in counties without Special Health Plans are enrolled in CSHCS' fee-for-service plan. Under this option, enrollees receive specialty services through CSHCS providers and enroll in Blue Cross/Blue Shield for care unrelated to their CSHCS qualifying condition.

The state's enrollment contractor, Maximus, is responsible for brokering managed care enrollment in all of the state's public-sector insurance programs, but the agency maintains a separate phone line and trained staff dedicated to the CSHCS program. When children are identified as potentially eligible for CSHCS (by primary or specialty care providers, or by local health departments, who may receive referrals from anyone in the community), their parents are asked to complete a CSHCS application and to join the CSHCS program. If they are found eligible, their names are forwarded to Maximus, which sends each family a packet of information that guides them through the process of selecting from among the plans available in their county. If the family chooses to enroll in a Special Health Plan, the child will be disenrolled from the mainstream health plan he or she was enrolled in under *MIChild*.

Once enrolled in a Special Health Plan, children are eligible for virtually all the benefits available under the Medicaid program. However, dental services (if they are not related to the CSHCS qualifying diagnosis) are provided through separate *MIChild* dental plans, and coverage of mental health services through the Special Health Plans is limited to 20 outpatient visits each contract year. Additional mental health services are provided through the community mental health system in each county.

A centerpiece of the CSHCS Special Health Plans is the care coordination services they offer. Each enrollee chooses a local care coordinator, who is housed in a community-based agency and is responsible for monitoring the child's care, and is assigned to a plan-based care coordinator, who is housed within the plan and is responsible for reviewing and authorizing services and responding to questions. The local care coordinator is responsible for developing an individualized health care plan for each child, which serves as a standing referral and authorization for all primary and specialty services each child may use in a year. Finally, each plan is also required to employ a "family-centered care coordinator" who works on the policy and system levels to assure that the plan's policies meet families' needs.

The Special Health Plans are paid on a capitated basis for all enrollees; however, at this time, the plans are not at risk for the cost of their care. For children who are enrolled in both *MIChild* and CSHCS, the plans are actually paid two capitation rates: one rate for CSHCS services, plus an additional *MIChild* capitated payment. The CSHCS rates are risk-adjusted based on the child's age, diagnosis, Medicaid eligibility status, and geographic region, while the *MIChild* rate is standard for all children in each age and sex category. The CSHCS rate is intended to cover the cost of specialty care for children ineligible for Medicaid, and the *MIChild* rate is the standard rate for comprehensive care for children who do not have special health care needs. Thus, the two together are expected to cover the full costs of care for children eligible for both programs. However, because the population is small and the costs of their care are unknown, the state plans to use a cost settlement process with each plan at the end of the program's first 15 months. That is, the state will pay the plans for any costs incurred above the capitation rates paid, or it will take back any amount paid that exceeds actual expenditures. Thus, the state, not the plans, is ultimately at risk.

In sum, Michigan's model of managed care for children with special health care needs shows significant promise. Its cautious use of risk-adjusted capitated rates, strong history of family involvement in program design and oversight, and support for community-based care coordination are not commonly found in mainstream Medicaid managed care systems and may prove to be excellent models for the care of CSHCN under SCHIP. However, the low number of children enrolled in the program (to be discussed later) indicates either that the number of CSHCN actually enrolled in *MIChild* is low or that many children in the state's CSHCS program have Medicaid or other private insurance and are thus not eligible for *MIChild*.

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Cost Sharing

Another key difference between SCHIP programs adopted as Medicaid expansions and those that represent separate programs relates to cost sharing. Medicaid-based SCHIP programs, unless they operate under Section 1115 demonstration waivers, must abide by Title XIX program cost-sharing rules, which limit states from charging premiums and imposing cost sharing on preventive services. On the other hand, states adopting new programs under SCHIP are permitted considerably more flexibility to impose cost sharing on enrollees. Although still prohibited from charging copayments for preventive care, separate programs may require premiums, copayments, and deductibles from virtually any family enrolled in SCHIP—for families with incomes below 150 percent of the FPL, cost sharing must be "nominal" and premiums cannot exceed $19 per month; for families with incomes greater than 150 percent, states may impose premiums on a sliding scale, as long as they don't favor families with higher incomes over those with lower incomes, and as long as aggregate cost sharing does not exceed 5 percent of family income.

Generally speaking, the states in this study have embraced cost sharing as appropriate—the vast majority of key informants we interviewed, including child advocates, believed that it was not unreasonable to ask families with earnings to contribute at some level to the cost of their children's care. Politically, the ability to impose cost sharing was critical to the passage of SCHIP in many states, according to state legislators. Among program administrators, cost sharing was seen as a tool to distinguish SCHIP from Medicaid and as a means for reinforcing the image that SCHIP was not a government welfare program, but rather a program that was "like private insurance." Even the Medicaid expansion states in this study, each of which has a 1115 waiver, have chosen to impose premiums and copayments upon higher-income families enrolling in SCHIP (Hill and Ullman forthcoming).

In interviews conducted for this study, nearly all key informants reported satisfaction with the levels at which cost sharing had been established, reporting that premiums and copayments seemed "nominal and affordable." Many state and local officials even expressed the belief that the presence of premiums and enrollment fees actually made their programs more attractive to families, particularly for those working poor who may view a free program as "welfare." Importantly, with the exception of those in Colorado, key informants also rarely reported hearing about or observing that cost sharing was imposing any barriers to either enrollment or service use.[9] However, once again, future quantitative analysis is required to verify whether this anecdotal evidence is valid.

Of course, families with CSHCN run a greater risk of incurring high out-of-pocket costs for health care because of their children's higher-than-normal rates of service use. Thus, SCHIP copayments, in particular, hold the potential to pose a disproportionate risk to these families. On the other hand, the Title XXI statute protects families from paying more than 5 percent of their incomes for SCHIP coverage.

When queried on this issue, key informants reported that they had not heard of cases in which families with CSHCN had experienced financial hardship as a result of

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SCHIP cost sharing. On the contrary, providers, advocates, and parents themselves were more likely to report that SCHIP cost sharing was "much cheaper" than what they were used to seeing in the private insurance market. Indeed, as illustrated in table 2, 7 of the 18 states in our study impose no copayments under SCHIP—Massachusetts, Michigan, Minnesota, New York, Ohio, Pennsylvania, and Wisconsin—and typical copayments in those states that do impose them are in the $5 to $10 range (for families with incomes between 150 and 200 percent of the FPL) for many of the services often used by CSHCN. Of note, three states in our sample take additional steps to shield families with CSHCN from out-of-pocket costs: California, Connecticut, and Florida waive copayments for families with children enrolled in the California Children's Services, *HUSKY Plus*, and Children's Medical Services programs, respectively. Although no other states waived premiums or copayments or set lower maximum caps on out-of-pocket expenses for families with CSHCN, cost-sharing rules were broadly described as reasonable and affordable by key informants, including parents of CSHCN and family advocates.

Table 2. *Copayment Policies by Service and Amount for Benefits Affecting CSHCN, in Dollars, by State and Federal Poverty Level*

	AL	CA[b]	CO	CT[b]	FL[b]	MS	MO	NJ	NC	TX	WA
Federal poverty level threshold (%)	150–200	100–250	<101 101–150 151–185	225–300	101–200	150–200	185–225 226–300	133–200 200–350	150–200	100–150 150–185 185–200	200–250
Inpatient hospital services ($)	5	0	0;0;0	0	0	0	0;0	0;0	0	2;5;10	0
Outpatient hospital services ($)	5	5	0;0;0	0	0	5	5;10	5;5	0	2;5;10	0
Physician services (office visits) ($)	5	5	0;2;5	5	3	5	5;10	5;5	5	2;5;10	5
Prescription drugs[a] ($)	1,3	5	0;1;3 or 5	3,6	3	0	0;10	1,5;5,10	6	1,2;5,10; 5,10	5
Outpatient laboratory and radiology services ($)	0	0	0;0;0	0	0	5	5;10	5;5	0	2;5;10	0
Inpatient mental health services ($)	5	0	0;0;0	0	3	0	0;0	0;0	0	2;5;10	0
Outpatient mental health services ($)	0	5	0;2;5	0;25;50 or 50%[c]	3	5	5;10	0;25	0	2;5;10	0
Inpatient substance abuse treatment services ($)	5	0	0;0;0	0	0	0	0;0	0;0	0	2;5;10	0
Outpatient substance abuse treatment services ($)	0	5	0;2;5	0;25;50 or 50%[c]	0	5	5;10	0;5	0	2;5;10	0
Durable medical equipment ($)	0	0	0;0;0	0	0	5	5;10	0;n/a	0	2;5;10	0
Hearing aids ($)	0	0	0;0;0	0	0	0	5;10	0;n/a	0	2;5;10	0
Corrective lenses (including eyeglasses) ($)	0	5	0;0;0	5	10	0	5;10	0;0	0	2;5;10	0
Physical therapy ($)	0	5	0;2;5	0	3	5	5;10	5;5	0	2;5;10	0
Speech therapy ($)	0	5	0;2;5	0	3	5	5;10	5;5	0	2;5;10	0
Occupational therapy ($)	0	5	0;2;5	0	3	5	5;10	5;5	0	2;5;10	0

Note: MA, MI, MN, NY, OH, PA, and WI impose no copayment requirements for children in their SCHIP programs. n/a = not applicable.
a. Different copayments within an income group represent rates for generic vs. brand-name drugs.
b. Copayments displayed are those that apply for regular SCHIP enrollees; CSHCN who are identified and enrolled in CA's, CT's, and FL's special programs are exempt from copayments.
c. Visits 1–10 have no copayment; visits 11–20 are subject to $25 copay; visits 21–30, lesser of $50 copay or 50 percent of cost of visit.

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It is worth pointing out, as well, that the type of cost sharing adopted by most SCHIP programs is fundamentally different, and potentially less burdensome, than that typically imposed by private policies. For example, no SCHIP program in this study uses coinsurance, a common component of private indemnity policies under which families must pay for 20 percent or more of the cost of every service they receive. Furthermore, among our study states only Texas imposes a deductible as part of its SCHIP cost-sharing design—deductibles, also commonly used in private insurance, represent sometimes large dollar sums that families must pay entirely before insurance policies begin picking up the costs of care.

Of course there were a few exceptions to these generally positive findings. In Florida, some parents who were accustomed to receiving assistance from their state's Title V/CSHCN program for free resented having to pay premiums for that care under SCHIP. This resistance, reported in a limited number of cases, resulted in families choosing to not enroll in SCHIP. Generally, however, these cases were exceptions to the much broader rule that families with CSHCN viewed SCHIP cost sharing as both affordable and less expensive than that which they were used to on the private market.

Crowd-Out "Waiting Periods"

In contrast to Medicaid, Title XXI was explicitly created to extend insurance to uninsured children. Therefore, the statute prohibits enrollees with other forms of "creditable" insurance from signing up for SCHIP. Furthermore, Congress was intent on avoiding the creation of a program that would substitute for existing coverage, either public or private, and thus required states to address so-called "crowd out" in their SCHIP plans and develop policies to limit its potential impact. Crowd out may occur when a consumer actively drops his or her coverage in order to sign up for a public program, or when an employer reduces or discontinues its offer of health benefits to employees, knowing that public coverage is available to take its place.

This study found that crowd out assumed a prominent place among issues debated during the design phase of most states' SCHIP programs. In most states studied, legislatures devoted significant time and energy to weighing the potential for crowd out under SCHIP and considering strategies to prevent it from occurring. Some policymakers argued that the potential for substitution was small—that low-income families simply did not have access to employer-based coverage and that efforts to prevent it might actually create barriers to enrollment. Others believed that the inclusion of crowd-out provisions was a sine qua non—omitting them from state SCHIP legislation would have been a "dealbreaker" in many of the study states (Westpfahl Lutzky and Hill in press).

As a result, the majority of states in this study implemented a variety of strategies to prevent or discourage crowd out, including cost sharing, using application questions that inquire about health insurance status, verifying insurance status against databases on private coverage, subsidizing employer-sponsored insurance, and imposing obligations on employers or insurers to not alter their coverage policies in response to SCHIP. States with the least onerous approach to addressing crowd out simply monitor the degree to which it is happening, usually specifying a maximum

acceptable threshold above which they promise to HCFA that additional measures will be taken.

However, the most common—and most aggressive—strategy for discouraging crowd out has been the imposition of "waiting periods," or specified periods of time during which a child must have been uninsured before being permitted to enroll in SCHIP. As shown in table 3, 11 of the 18 study states have adopted waiting periods ranging from two to six months in length (Westpfahl Lutzky and Hill in press).[10]

Table 3. *Waiting-Period Policies*

		Exception Policies			
			Relevant to CSHCN		
State	Length of Waiting Period (months)	Lost Insurance through No Fault of Their Own	Individual Insurance Policies	High Insurance Costs	Specific to CSHCN
AL	3	X			
CA	3	X	X		
CO	3	X		X	
CT	6	X		X	
MI*	6	X	X		
MO	6	X			
NJ	6	X	X		
NC	2	X			X
TX	3	X		X	
WA	4	X		X	
WI	3	X			
Total	11 of 18 states	11	3	4	1

* Michigan also considers geographic access-to-care issues and waives waiting periods for those children whose private coverage does not afford them access to providers within a reasonable distance.

Waiting periods have emerged as the most controversial of crowd-out prevention policies; some key informants argued that they create inequities for parents who have "done the right thing" by purchasing insurance for their children in the past, by preventing them from enrolling in SCHIP even if it offers a more comprehensive and affordable alternative to their current coverage. This circumstance, we found, was particularly applicable to parents of CSHCN. Key informants interviewed for this study, including parents, reported that many families earning too much income to qualify for SSI and Medicaid have sought and purchased insurance for their CSHCN on the private market. Often, this coverage was described as limited in scope or

expensive due to significant cost-sharing requirements in the form of deductibles, coinsurance, and copayments. For these families, even though SCHIP may offer a considerably more attractive alternative than their private coverage, waiting periods effectively preclude them from even considering a switch to SCHIP: Although a family with healthy children might contemplate dropping their private coverage and "going bare" for a short time, parents with a sick child simply may not feel that they can risk dropping that child's coverage for even the shortest waiting period. Consequently, children who, arguably, might benefit most from SCHIP's affordable and comprehensive health coverage may often be denied access to it.

All states permit certain exceptions to their waiting-period policies. However, typically, these exceptions do not relate to issues of underinsurance and address only situations in which a family loses coverage within the specified waiting period through no fault of its own. For example, most states excuse families from waiting periods and allow them to enroll their children in cases in which an employer recently stopped offering dependent coverage, or an applicant has recently lost his or her job (and consequently, insurance), moved, changed jobs, or had COBRA benefits expire.

In a small but growing number of states, however, we also saw exceptions policies that consider the cost of a family's current coverage and excuse waiting periods for cases in which family costs exceed some threshold of reasonable affordability. Specifically, as shown in table 3:

- Colorado waives its three-month waiting period for families with employer-based coverage when the employer contributes less than 50 percent of the cost of their premium;
- Connecticut waives its six-month waiting period for families who pay more than 5 percent of their gross income for their insurance coverage;
- California, Michigan, and New Jersey[11] waive their waiting periods for children who are covered by individual policies (in recognition of the fact that such coverage is typically very expensive);
- Texas's three-month waiting period is waived for families that pay more than 10 percent of their income on family coverage; and
- Washington waives its four-month waiting period for families paying more than $50 per month, out-of-pocket, for employer-sponsored health care coverage.

Although these exceptions are designed to help any family bearing a heavy financial load for their child's current private coverage, one might expect that such policies may especially help parents of CSHCN, given their greater likelihood of incurring high out-of-pocket costs for their children's care.

Officials in North Carolina, however, have recently chosen to more explicitly help families with CSHCN. In October 2000 the state received federal approval of a plan amendment whereby its two-month waiting period will be waived for families with a child with special health care needs who have had their coverage terminated or reduced in scope so that it does not adequately cover the child's long-term disability. (The amendment became effective November 1, 2000.)

CSHCN Prevalence among SCHIP Enrollees

At this time, most of the states in this study have had two or more years of experience implementing at least some components of their SCHIP programs. Among those with special initiatives for serving children with special needs, we asked for reports of how many CSHCN had been identified or served by their programs. For contextual purposes, we also asked state officials how many CSHCN they had *expected* to find among SCHIP enrollees. In our previous analysis of this issue, states reported much lower prevalence of CSHCN than expected: Through late 1999, rates ranged from less than 1 percent of all SCHIP enrollees in Connecticut's *HUSKY Plus* program to roughly 8 percent in North Carolina's *Health Choice* program, based on an analysis of ICD-9 diagnosis codes of enrolled children at that time (Schwalberg, Hill, and Mathis 2000). Notably, no state among the five included in the study was serving anywhere near the estimated 17 percent prevalence of CSHCN among their population of uninsured put forth in recent research literature (Newacheck et al. 1998).

Even with another year of experience to draw on, however, it appears that states have not found large numbers of CSHCN among their SCHIP-enrolled population. Although states had very different assumptions regarding how many CSHCN they would enroll and reported "prevalence" in very different ways, the data that we could obtain from those states with special initiatives for CSHCN are provided below.

- Connecticut officials originally estimated that 8 percent of *HUSKY B* enrollees would be eligible for *HUSKY Plus Physical*, or 1,800 of the 22,300 children estimated to be eligible for *HUSKY B*. Of these, an estimated 400 children were expected to have mental health needs triggering a referral to *HUSKY Plus Behavioral*. Through October 2000, though, only 143 children had been served by the *Plus Physical* program and only 11 children were enrolled in *Plus Behavioral*—just 9 percent of expected *Plus* enrollment and less than 3 percent of total *HUSKY B* enrollment.
- In Florida, state officials expected to enroll approximately 5 percent of all *KidCare* enrollees in the Children's Medical Services system. By October 2000, about 5,200 of 184,000 enrollees had been placed in the program, a participation rate of roughly 3 percent.
- Michigan officials estimate that fewer than 300 of the 16,300 children enrolled in *MIChild* are also enrolled in the CSHCS program, or less than 2 percent.
- In North Carolina, well below $1 million in *Health Choice* expenditures have been devoted to covering wraparound services for CSHCN—less than 1 percent of total spending.
- Alabama has not yet implemented its *All Kids Plus* program and thus has not served any CSHCN through its special initiative. However, state officials estimate that 9 percent of *All Kids* enrollees will have special needs and be served through the *All Kids Plus* network.

- California was not able to provide updated data on children enrolled in CCS. As of August 1999, however, an estimated 2,000 of *Healthy Families'* then-total enrollment of 152,000 were in the CCS carve-out, or just 1.3 percent.

In our previous study, many theories were offered by state officials as to why these prevalence rates were lower than what they had expected (Schwalberg, Hill, and Mathis 2000). With an additional year to reflect, key informants interviewed for this study offered similar potential explanations, including the following:

- ***Insufficient outreach.*** As described above, no state targeted any of its marketing efforts to CSHCN and their families, and only relatively low-level efforts have been directed at pediatric providers likely to serve CSHCN, as well as families participating in Title V/CSHCN programs. Recent research has also generally found considerable confusion among Americans regarding who is and is not eligible for SCHIP and Medicaid (Kenney, Haley, and Dubay in press); perhaps this confusion extends to families with CSHCN who might not see SCHIP as a program intended to serve their particular needs.
- ***Inaccurate and inadequate identification.*** States were also dissatisfied with the ability of their systems to identify CSHCN among the SCHIP-enrollee population. As reported above, although the majority of states studied make no attempt to identify CSHCN, even those with special programs have found single questions on application forms an inefficient mechanism, and fear that reliance on provider referrals, especially in a managed care environment, is not sufficient.
- ***Programs are still new.*** Despite an additional year of experience, state officials still feel that their programs are relatively new and unknown and that, with maturity, they will attract more customers.
- ***CSHCN may not be as prevalent among the uninsured as originally believed.*** A very intriguing theory posed to explain why fewer CSHCN were turning up in these programs than originally expected was that, perhaps, these children are not as likely to be uninsured as other children at the same income level. Despite national evidence to the contrary (Almeida and Kenney 2000), some informants speculated that low-income children with chronic illnesses and disabilities might be less likely to be uninsured, for two reasons: State Medicaid programs are likely to already serve many of those with the most severe conditions by virtue of their eligibility for SSI; and among working families with too much income to qualify for Medicaid, parents with CSHCN are likely to have gone to great lengths to secure insurance for their children through their jobs or other means. Thus, CSHCN might be underrepresented among children eligible for SCHIP. In Michigan, for example, a recent analysis found that 90 percent of all children in the state's Title V/CSHCN program have Medicaid or other private insurance, thus rendering them ineligible for SCHIP. In a national survey of more than 2,000 families with CSHCN at all income levels, 97 percent reported having health insurance, with a roughly two-thirds/one-third split between those with private versus Medicaid coverage (Krauss et al. 2000). Furthermore, some state officials noted the possibility that the CSHCN who were enrolling in SCHIP might have less complex conditions (such as asthma) and might be having their needs adequately met by states' mainstream systems. In other words, they have

not required the extra services and supports available through specialty and wrap-around systems.

- ***Waiting periods may be erecting barriers for underinsured CSHCN.*** Once again, state officials and family advocates are increasingly concerned that waiting periods, designed to discourage families from dropping existing private insurance to sign up for SCHIP, may have a disproportionate and particularly negative impact on families with CSHCN. As discussed above, the problem of underinsurance may be widespread among privately insured persons with disabilities; high deductibles and coinsurance rates, annual and lifetime benefits limits, and coverage exclusions can combine to make private health insurance both expensive and limited in scope, and thus inadequate to meet the needs of a disabled person. The Title XXI statute, however, considers children in this circumstance to be insured, and thus ineligible for SCHIP. During our site visits, many SCHIP officials and family advocates regretted that general policies to prevent crowd out might be, by extension, preventing underinsured CSHCN from enrolling in a system that might provide them with broader and more affordable coverage for their conditions.

In sum, it appears that a number of complex factors may be combining to constrain the enrollment of CSHCN into SCHIP.

Conclusions and Implications for Future Policy

Immediately upon the passage of the Balanced Budget Act of 1997 and the creation of SCHIP under Title XXI, many debates were waged over how states would use the flexibility afforded by the law to expand coverage, and whether Medicaid expansions or the creation of separate programs offered states the best opportunity for increasing children's coverage under SCHIP. Commonly cited advantages of expanding Medicaid included the entitlement protection it offered children, the breadth of coverage afforded by the EPSDT program, and the administrative efficiency of building upon existing infrastructures of state agencies, rules, systems, and networks. Separate programs, on the other hand, were seen as offering states the opportunity to avoid perceived chronic access problems under Medicaid and to design new models of care patterned after mainstream private insurance and free of the welfare-related stigma associated with Medicaid. For uninsured children with special health care needs, the potential downsides of separate programs—no entitlement protection, the ability to limit benefit packages, and the freedom to impose higher cost sharing—supported arguments that Medicaid expansions offered a safer route.

Today, even with two to three years of implementation experience to observe, it is premature to judge whether separate programs or Medicaid expansions are better serving children in general or CSHCN in particular. Ultimately, it is probably impossible to reach such a sweeping conclusion, for historical and environmental contexts vary considerably across the states, and individual circumstances in each have dictated which strategy has been chosen by policymakers as offering a more viable approach.

Based on this study, however, we can observe that most states did not focus particular attention on CSHCN during the design phases of their SCHIP programs. Rather, policymakers grappled with the larger question of whether to expand Medicaid or adopt separate programs under SCHIP. Regardless of the choices made, it can also be said that states have tended to subject CSHCN to the same rules as all other children enrolling in SCHIP and have inserted CSHCN into the same systems of care used by the general SCHIP population. In an encouraging number of states with separate programs, however, we can also see that special initiatives have been designed that attempt to address the needs of children with disabilities and to provide more "Medicaid-like" coverage; these efforts tend to mitigate the potential differences between Medicaid and separate programs.

More specifically, this study has attempted to answer a number of questions regarding how, and to what degree, SCHIP programs have accounted for the special needs of CSHCN and designed policies to address them. What we found was mixed: In some key implementation areas, fascinating innovations have emerged; in others, little or no accommodation is being made. Key findings are summarized below.

- ***Outreach, Enrollment and Identification.*** In none of the study states' SCHIP marketing campaigns did we see any overt efforts to reach out to CSHCN and their families and target them for enrollment purposes. Rather, states focused their energies on much broader campaigns to raise the general public's awareness of the availability of coverage under SCHIP and on efforts to simplify eligibility rules and application processes. The few states that have implemented systematic processes for identifying CSHCN among children who enroll in SCHIP have experienced limited success with these efforts. A number of states did, however, describe efforts within their Title V/CSHCN programs to contact families with uninsured children, and their doctors, to inform them of coverage availability.

- ***Benefits.*** Not surprisingly, we found benefit packages under separate programs to be more limited than those covered by Medicaid. However, coverage policies in separate programs are quite broad—often described as "much better" than typical private coverage—with exceptions and limits in coverage less extensive than many initially feared. Although key informants in the states could not identify cases in which children needed benefits that were not covered, it can be observed that many of the services often needed by CSHCN are precisely those that are either omitted or subject to limits under SCHIP, such as case management, nonemergency transportation, rehabilitative therapies, and behavioral health services; this presents reasonable cause for concern. Of special interest, 2 of the 14 states we studied that have separate programs—Connecticut and North Carolina—have designed wraparound benefit packages for CSHCN intended to supplement the basic coverage available to all children and to extend more open-ended, EPSDT-equivalent coverage to CSHCN in separate programs.

- ***Service Delivery.*** The broader question of whether to rely on Medicaid delivery systems or design whole new networks for SCHIP tended to overshadow the narrower issue of which systems of care should be used to serve CSHCN. In almost every state, SCHIP programs are relying on managed care, and in most states, no special provisions are made to help ensure that appropriate access is extended

to CSHCN in these arrangements. Once again, this may be reason for concern. However, key informants interviewed during our site visits, including family advocates, could report few or no cases in which delivery systems seemed to be failing to meet the needs of CSHCN. Furthermore, three states in our study have designed "carve-out" or specialized managed care systems to serve CSHCN enrolled in SCHIP, systems specifically tailored to include the providers and supports often needed by CSHCN and their families. Early impressions in California, Florida, and Michigan are that these systems offer significant promise for providing more comprehensive and coordinated care for CSHCN than mainstream managed care systems.

- ***Cost Sharing.*** SCHIP has granted states considerable new flexibility to impose cost sharing—in the form of premiums and copayments—on eligible families. Given the likelihood that they will consume services at rates greater than the norm, CSHCN and their families are particularly vulnerable to high out-of-pocket costs as a result of copayment policies, and only two of the study states reported policies that exempted CSHCN from cost sharing or that somehow protected them from undue expense. On the other hand, the Title XXI statute protects any family from spending more than 5 percent of its income for SCHIP coverage, and early impressions are that cost-sharing amounts under SCHIP are nominal and affordable. Indeed, they were often referred to as "much lower" than those found in private insurance policies. Key informants interviewed for this study typically could not cite cases in which they had heard of families with CSHCN that were enduring high financial burdens as a result of their participation in SCHIP.

- ***Crowd-Out Waiting Periods.*** Concern over the potential for SCHIP to substitute for existing private sector health insurance coverage was widespread among state legislators during the programs' design phase. As a result, most states now employ a range of strategies designed to prevent crowd out; most commonly, waiting periods have been imposed to require children to have not had insurance for a specified period of time before being permitted to enroll in SCHIP. When asked about the perceived impact of policies such as waiting periods, SCHIP officials and family advocates often reported that CSHCN and their families appeared to be disproportionately affected; more precisely, underinsured CSHCN were prohibited from enrolling in the potentially more comprehensive and affordable SCHIP program in their state due to waiting periods. Encouragingly, six states will exempt families from waiting periods if current coverage is imposing a significant financial burden, and one state recently enacted a policy that entirely exempts families with CSHCN from waiting periods.

- ***Prevalence of CSHCN among SCHIP Enrollees.*** For a variety of complex reasons, it appears that states continue to struggle to identify and enroll large numbers of CSHCN in their SCHIP programs, even with special provisions designed to better serve the population. Only between 1 and 8 percent of SCHIP enrollees in the five states that could report such data have been identified as having special needs, far below national estimates that the prevalence of CSHCN could be as high as 17 percent.

Looking ahead, it is clear that more research is needed to determine how well CSHCN are faring under SCHIP. This study has provided an early look at the general policies implemented by states and discussed their implications for CSHCN. It has also provided detailed descriptions of promising initiatives being enacted by some states in an attempt to make SCHIP programs more responsive to the needs of this vulnerable population. Although many lessons can be learned from these early experiences, more rigorous quantitative analysis is needed to begin developing a more precise understanding of the access, use, outcomes, and satisfaction of CSHCN and their families. Specific suggestions for future research include, but are not limited to, the following:

- Comparisons of rates of use of various services by CSHCN and children generally, and within Medicaid versus separate state programs;
- Comparisons of utilization rates of selected services in states with and without cost sharing;
- Comparisons of rates of enrollment in states with and without waiting periods, and analysis of the impacts of different exceptions policies; and
- Comparisons of access, service use, expenditures, and family satisfaction in mainstream versus specialized systems of care.

A strategy that might facilitate federal and state monitoring of SCHIP's effects on CSHCN would be to apply to Title XXI programs selected provisions of HCFA's recently released interim criteria for states enrolling CSHCN into managed care arrangements (although, presumably, state officials might resist additional regulatory oversight in this area).

However, this study, building on previous work, appears to reinforce the finding that proportionately fewer children with special health care needs are being identified and enrolled in SCHIP than had widely been anticipated, even in states with special initiatives designed to better serve CSHCN. Although several possible explanations have been offered for the low prevalence of CSHCN among enrollees, it was suggested by many key informants that rates of uninsurance among CSHCN may be lower than those presented in recent research. Furthermore, for those families whose CSHCN are insured, but perhaps underinsured for their conditions, waiting period policies implemented to discourage or prevent crowd out may be posing a particular barrier to enrollment. Indeed, limited research suggests that it is likely that a significant proportion of privately insured families with CSHCN are underinsured with regard to the coverage of their children.

For such families, SCHIP may offer an alternative that is both broader in scope and more affordable than the private insurance they currently possess. Yet the statutory priority of SCHIP to target uninsured children, and the law's prohibition against enrolling those with creditable insurance, seems to rule this alternative out. For families with relatively healthy children who have dependent coverage and are underinsured, waiting periods (especially those of short duration) may not pose a particular barrier; such families may choose to drop their private coverage, "go bare" during the waiting period, and then enroll in SCHIP. Such an option is usually out

of the question, however, for families with sick children, who cannot afford to take the risk of dropping their existing coverage.

This situation raises a critical question, and challenge, for the Title XXI program: Although primarily designed to extend health insurance to uninsured children, can SCHIP also be amended to address the needs of *underinsured* children?

Policymakers may, for equity's sake, consider two possible changes in current policy that would allow the program to address the needs of the underinsured:

1. ***Permit SCHIP coverage to "wrap around" existing private health insurance for selected priority populations, such as children with special health care needs.*** The Medicaid program has always been permitted to wrap around private coverage. Federal policy stipulates that Medicaid is to serve as the payor of last resort for persons dually insured, and much effort is made by state Medicaid administrators to coordinate benefits for such persons and ensure the integrity of the Medicaid system. SCHIP programs could be modified to play this same role, if not for all privately insured children, then for those with chronic illnesses and disabilities who are at risk for underinsurance. Such a change would not, in fact, represent an easing of crowd-out policies; it would reinforce the fact that SCHIP coverage was not substituting for private coverage, while also permitting the program to fill in gaps that may be present in that private coverage.

2. ***Encourage or require states to broaden their waiting period exceptions policies to allow children with special health care needs to drop private coverage if that coverage is deemed significantly limited or expensive.*** A more overt policy change that would actually permit crowd out under selected circumstances, this would expand what is already occurring in a handful of states where exceptions to waiting periods acknowledge that some families' private coverage, although creditable, may be very expensive or limited and, therefore, that children with such coverage should be permitted to switch to SCHIP.

This study has provided preliminary evidence that SCHIP programs, in spite of (or perhaps because of) their great diversity, appear to be providing relatively broad and affordable coverage to low-income children, including children with special health care needs. It has also revealed that an encouraging number of states have implemented special provisions—in the areas of benefits coverage, service delivery design, and crowd-out prevention—to make SCHIP more responsive to the needs of CSHCN and their families. As programs mature, it is reasonable for policymakers to consider possible amendments to Title XXI, such as those suggested above, that might improve the program's ability to serve the various subgroups of children who are particularly vulnerable.

Appendix

Key SCHIP and Medicaid Contacts in the Study States

Alabama — Gayle Sandlin and Mike Murphy

California — Sandra Shewry and Doug Porter

Colorado — Barbara Ladon and Dean Woodward

Connecticut — David Parella

Florida — Rose Naff, Bob Sharpe, and Phyllis Sloyer

Massachusetts — Mark Reynolds and Pat Canney

Michigan — Denise Holmes and Bob Stampfly

Missouri — Greg Vadner

Minnesota — Mary Kennedy

Mississippi — Theresa Hanna and Maria Morris

New Jersey — Michelle Walsky

New York — Judy Arnold

North Carolina — June Milby and Tom Vitaglione

Ohio — Sukie Barnum

Pennsylvania — Patricia Stromberg

Texas — Jason Cooke

Washington — Steven Wish and David Hanig

Wisconsin — Peggy Bartels

Notes

1. This analysis of the National Health Interview Survey on Disabilities used a fairly broad definition developed by the federal Maternal and Child Health Bureau: that *Children with Special Health Care Needs* are those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally (McPherson 1998). As there is no accepted method of defining the "at-risk" population, this estimate only counted children with existing special health needs.

2. The SCHIP Evaluation is primarily funded by The Robert Wood Johnson Foundation and the David and Lucile Packard Foundation.

3. Site visits were conducted between June 1999 and April 2000. Due to particular circumstances surrounding the implementation of SCHIP in three states—Minnesota, Texas, and Washington—multiple and detailed telephone interviews were conducted with a variety of key informants there in lieu of site visits. These telephone interviews were conducted in the summer and fall of 2000.

4. This portion of the evaluation was primarily funded by the David and Lucile Packard Foundation through a grant to the National Policy Center for Children with Special Health Care Needs, for whom the Urban Institute served as a subcontractor. A separate paper, *New Opportunities, New Approaches: Serving Children with Special Health Care Needs Under SCHIP*, based on the findings in these five states, was published in June 2000 (Schwalberg et al. 2000).

5. The federal Title V program provides block grants to states to support systems development and service delivery initiatives for mothers, children, and children with special health care needs. The CSHCN components of states' Title V programs exist to foster the development of family-centered, community-based, comprehensive, coordinated, accessible, and culturally competent systems of care for CSHCN. To carry out this mission, programs perform a variety of activities and functions that can involve the direct delivery and financing of health services to individuals, population-based services, and core public health functions including needs assessment, policy development, and quality assurance. In many cases, Title V programs will provide families with support, both financial and logistical, in obtaining services not covered by private insurance. Although specific eligibility criteria vary considerably from state to state, Title V programs typically target lower-income families and children with chronic conditions and disabilities identified in the state's program plan.

6. Under the Omnibus Reconciliation Act of 1989, the EPSDT portion of the statute was amended to require states to cover any service needed by a child to treat a condition identified during an EPSDT screen, even if that service was not explicitly covered by the state plan.

7. In Pennsylvania, four of the seven plans with whom the state contracts are Blue Cross/Blue Shield organizations; the other three plans are Aetna/US HealthCare, AmeriChoice, and Three Rivers Health Plan.

8. The Balanced Budget Act of 1997 allows states to enroll their Medicaid populations in managed care without a waiver; however, Medicaid-eligible children with special health care needs (including those eligible for SSI, Title V CSHCN services, foster care or adoption assistance programs, or "Katie Beckett" home-based care programs) may not be required to enroll in managed care without a waiver from the Health Care Financing Administration.

9. A notable exception to this finding was in Colorado, where higher levels of premiums were charged to families at lower incomes, and where a statewide indigent care program continues to offer free or low-cost/sliding scale care to individuals who need it. In that state, many instances were cited in which families chose to continue receiving care through the indigent care program rather than sign

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up for SCHIP. Recognizing this, Colorado officials were considering proposals to reduce or eliminate premiums under SCHIP at the time of this writing.

10. This proportion is consistent with the national picture, where 34 of the 51 states (including the District of Columbia) impose waiting periods to prevent crowd out.

11. New Jersey waives the waiting period for children covered by individual insurance policies who live in families with incomes below 200 percent of FPL only.

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